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ABSTRACT

Six papers prepared for presentations at the 10th Mary E. Switzer Memorial Seminar focus on topics related to transition from school to work and independence for disabled youth. Each paper concludes with excerpts of reviews and comments, followed by recommendations which are presented to further stimulate thinking, discussion, and action. The following authors and titles are included: "An Historical Background of Transitional Employment Programs and a Perspective on the Future" (M. Tooman); "Facing New Challenges with Old Strategies: Needed Reform in Managing Adult Services for Disabled Citizens" (R. Bruninks, K. Lakin, and B. Hill); "Public Policies Affecting Transition from School to Independence: Removing the Barriers" (R. Conley); "Costs and Other Economic Considerations in Transition Programming" (D. Hanks); "Families in the Transition Process: Important Partners" (B. Mendelsohn and J. Mendelsohn); and "Employment: A Vital Process in Transitions" (W. Kiernan). The monograph concludes with three special papers: "A Transition Initiative: Horticulture Hiring the Disabled" (C. Richman); "Federal Activities to Improve the Transition from School to Adult Services" (J. Elder); and "Some Thoughts on Transition: A Current Appraisal" (E. Martin). (JW)

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The Transition to Work and Independence For Youth With Disabilities

A Report of the Tenth Mary E. Switzer Memorial Seminar
May, 1986

Published by
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633 South Washington Street
Alexandria, Virginia 22314

Editors: Leonard G. Perlman and Gary F. Austin

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Leonard G.
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TO THE EDUCATIONAL RESOURCES

A Memorial Tribute

To Mary E. Switzer

1900 - 1971

Few people realize that she had a satisfying and fully successful career in federal government employment that spanned several decades prior to her formal entry into the field of rehabilitation. She was fifty years old when she became director of the Office of Vocational Rehabilitation in 1950, and she brought to the position a superior intellect and ability. Her many talents and experiences in economics, the legislative process, government administration, health, welfare and public education were only a few of the composite assets brought with her. She entered the movement at a crucial point in its evolution. It was a time in which difficult decisions had to be made between maintaining the status quo or moving to a larger and unknown future but with increased opportunity to serve tens of thousands of disabled persons yet in need.

Following a life pattern in support of increased services to people and a more responsive and humanitarian government to changing human needs, she readily committed herself to the less certain but more hopefully expanded future for rehabilitation. The rest is history. The breadth and humanity of Mary Switzer are stamped forever in the passage of Public Law 565 with its research and demonstration features, its concern for rehabilitation education, its mandate to construct necessary rehabilitation facilities, its totally new characteristic of international efforts and cooperation regarding rehabilitation, and perhaps, above all, in its expanded funding base for more personnel and programs for those in need of rehabilitation services. In the years that followed, she went on to even greater legislative and governmental leadership heights in behalf of both disabled and disadvantaged people.

(continued on back inside cover)

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Published May, 1986 -- Held November 13-15, 1985, Gallaudet College, Washington, D.C.

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Sponsors of the Tenth Switzer Memorial Seminar & Monograph

★ *Administration on Developmental Disabilities*
(U.S. Department of Health & Human Services)

★ *Gallaudet College,*
Washington, D.C.

★ *Human Resources Center,*
Albertson, New York

★ *Jewish Vocational Service,*
Chicago, Illinois

★ *National Association of Rehabilitation Secretaries (NARS)*

★ *National Council for Therapy and Rehabilitation*
Through Horticulture,
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★ *National Rehabilitation Counseling Association (NRCA)*

★ *President's Committee on Employment of the Handicapped*

★ *World Rehabilitation Fund, Inc.,*
New York, New York

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Preface

Millions of United States citizens are denied access yearly to the hope and promise our society holds for the good life simply because of physical or mental disability. The recent social movement highlighting the need for emphasis on transition from school to work provided the opportunity to insure access for all citizens to the benefits derived from work within this society.

In order to take advantage of this opportunity, we must continue to educate the general public to insure that an increased awareness and sensitivity exists in relation to the problems faced by the individuals with disabilities in our society. Such increased awareness will help to guarantee that transition is here to stay. It also will help insure public support for the increased funding necessary to address the basic problems related to transition.

Unemployment rates for adults with disabilities are conservatively estimated at 50% for males and 76% for females. The majority of those employed are underemployed (U.S. Commission on Civil Rights, 1983) and over 30% live at or below the official poverty level. Yet, the major federal program designed to remedy these problems, the State-Federal Vocational Rehabilitation Service Delivery program, is funded at such a minimal level that only one in 20 requiring services can access them. This funding issue presents a major barrier to effective transitional service delivery.

It is estimated that between 250,000 and 300,000 students with special needs leave public education programs each year and are expected to integrate into a variety of post secondary and career settings (Will, 1984). This data does not reflect those lost from the system, the 'drop-outs' who have received special education services estimated to be at least 30% (Hasazi, Horden and Roe, 1985). The 'drop-out' rate for minority language students with disabilities indicate a rate four times that of individuals who are from an English language background (Spring, 1976, Survey of Income and Education, U.S. Bureau of Census). The basic drop-out problem must also be addressed as part of the transition movement.

For those who do graduate, much more emphasis must be placed on transitional needs. Coff and Phelps (1983) findings highlight this need. They reported that, in a random sample of secondary level students with disabilities, only 49.1% of EIP's were found to have a vocationally related goal. Their findings also highlighted the lack of articulation that commonly exists between special, regular, and vocational educators at the secondary level when developing and implementing programs for students who are handicapped.

Similarly, Brown and Kayser (1981) argued that varying degrees of articulation existed between secondary level service providers and post secondary service providers such as college personnel, private vocational programs and vocational rehabilitation. A need exists to reexamine and overcome these articulation problems.

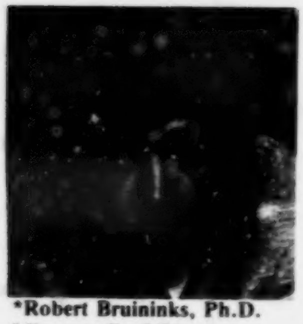
Quality transitional programing must address and resolve these basic problems if new approaches inherent in the movement are to present more than just band-aid approaches. Communication is the key. I would hope parents, educators, rehabilitation service delivery specialists, and administrators are able to use that key to help insure that all individuals with disabilities are prepared to transition from school into the community, and be able to access the work force, raise a family, and live as independent and happy a life as possible.

Amos Sales
President
National Rehabilitation Association

Format of the Monograph

The format of this monograph closely follows the proceedings of the seminar. Each of the six "Action Papers" specifically prepared for the seminar are shown as chapters and include a section on excerpts of "reviews" and comments of each paper made by the participants. At the end of each chapter, where appropriate, there is a summary of recommendations for action in the areas of policy and program development, service delivery, research, training and legislation. This is listed in an easy-to-use style. In addition, there are special invited papers by prominent persons in the field working on projects associated with the topic of this seminar.

Switzer Scholars



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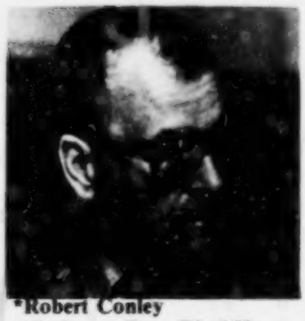

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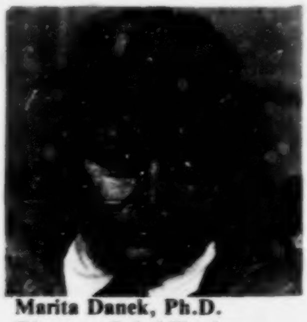

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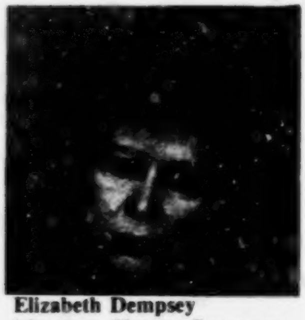

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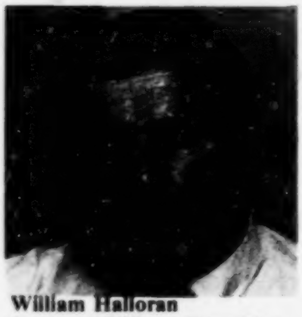

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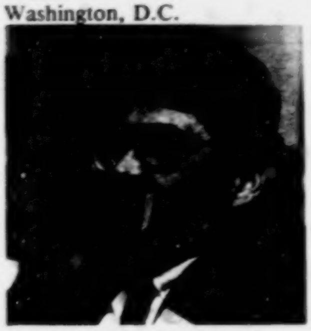

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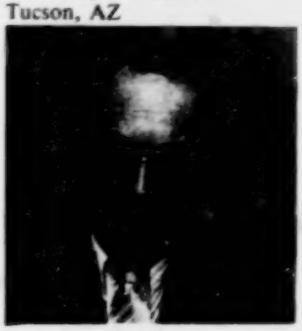

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Introduction

The Mary E. Switzer Memorial Committee was established in 1973 by the National Rehabilitation Association as a living memorial to Mary E. Switzer. This tribute was spearheaded by her colleagues and friends with the objective that each year a major topic of interest in the rehabilitation of disabled persons would be explored in depth by a small number of experts in the topic under study. Those selected to participate in this intensive working group would be designated as Mary E. Switzer Scholars by certificate.

Transitions -- Focus of the Seminar

It is very fitting that the tenth anniversary of the Switzer Seminars was devoted to the pressing issue of youth in the transition process. This area has received renewed emphasis and attention from Special Educators and Rehabilitation Counselors in the past few years, the stimulus being Public Law 94-142 and the thousands of beneficiaries of this law which celebrated its tenth anniversary of enactment this year.

The memorial seminar was held in Washington, D.C. from November 13-15, 1985 and was hosted by Gallaudet College. Sponsors of the seminar were the Administration on Developmental Disabilities (U.S. Department of Health & Human Services); Human Resources Center, Albertson, NY; Jewish Vocational Service, Chicago, IL; National Association of Rehabilitation Secretaries; National Rehabilitation Counseling Association; President's Committee on Employment of the Handicapped, World Rehabilitation Fund, New York, N.Y., and the National Council for Therapy and Rehabilitation Through Horticulture.

The Seminar

Welcomes were provided by Jerry Lee, President of Gallaudet College and David Martin, Dean, School of Education & Human Services, Frank R. Zieziula, Chairman, Department of Counseling and Marita Danek, Director, Rehabilitation Counseling. A special welcome was made by former Switzer Scholar, Jack Victor (1982) representing the Human Resources Center, New York.

Keynote speaker was Jean Elder, Commissioner of the Administration on Developmental Disabilities, U.S. Department of Health & Human Services. A special presentation was made by Thomas J. Fleming, U.S. Office of the Special Assistant to the President for Consumer Affairs.

The Switzer Planning Committee, in outlining the goals and direction of the seminar, provided a broad array of topics for the Scholars. Examples of the subtopics are shown by the titles of the papers written for the seminar and appear in this report as chapters.

* **An Historical Background of Transitional Employment Programs with a Look Toward the Future.** *By Marvin L. Tooman*
* **Facing New Challenges with Old Strategies: Needed Reform in Managing Adult Services for Disabled Citizens.** *By Robert H. Bruininks, et al.*
* **Public Policies in Transitions from School to Independence: Removing the Obstructions.** *By Ronald W. Conley*
* **Costs and Other Economic Considerations in Transition Programming.** *By Dale Hanks*
* **Families in the Transition Process: Important Partners.** *By Barry L. Mendelsohn and Jacqueline Z. Mendelsohn*
* **Employment: A Vital Process in Transitions.** *By William E. Kiernan*

The above subtopics provided a foundation of the three-day program. The chapters were sent to all Switzer Scholars in advance of the seminar. Reviews and comments of each chapter were completed prior to the seminar and served to prepare the scholars for the intensive deliberations that took place at the seminar.

Many feelings, ideas and recommendations that emerged from the Tenth Mary Switzer Memorial Seminar are found in this monograph. We do not expect everyone to agree with all of the contents, but hope that they will stimulate thought and action in the area of transitions of youth. The Switzer Scholars represented a broad cross-section of experiences and training and came from a variety of professional settings and sections of the nation. As such, the discussion was spirited, exciting and diverse in terms of expressed desires and issues that needed immediate attention..

It is the hope of the Switzer Memorial Committee that the contents of this monograph will stimulate interest and action in behalf of those persons who need a broad range of services, sensitivities and commitment to insure their full citizenship and independence.

Scholarly Observations of the Seminar

This Memorial Seminar sparked numerous debates and many ideas were expressed about a wide range of issues that will help shape the direction of rehabilitation services in the years to come. The following quotes from Switzer Scholars provides a brief overview of the seminar.

"As I look at the school to work transition program of the '60's and '70's and those of today I see some distinctive differences. First, the impact of P.L. 94-142 and Section 504 of the Rehabilitation Act has motivated educators to take a new look at disabled students, particularly those with significant handicaps, and the current effort is on providing relevant, marketable vocational skills. In the '60's and '70's employers were more peripherally involved. Today, using their resources and leadership, they are becoming the integral part of successful programs. We are discovering the importance of the family in the transition process. Currently we are trying to involve parents in a meaningful, constructive manner. Finally, unlike the '60's and '70's, there are some more successful disabled workers around, particularly at the professional and technical levels. These workers can serve as examples and mentors for students with disabilities -- students who can look to a bright future with technological aids and advances and a shrinking labor force whose skills will be in demand for a variety of new jobs."
--Richard "Dick" Sheppard

"Our ultimate goal? We hope to see kids who feel that their growth toward adulthood is a shared experience, where their potential is understood and encouraged by parents, teachers, counselors, and other practitioners. We recognize that many disabled young adults will reach a limited degree of independence, but let that level be the top of their ability, the best of their effort. We seek a time when parents and professionals can say, 'we knew what we had to do; we knew what we had to work with; lots of good people helped along the way; and we're proud of what we've accomplished.'"
--Barry Mendelsohn & Jacqueline Z. Mendelsohn

"The argument has been advanced that coordination of services for severely handicapped adults can be enhanced through application of behavior theory, experimentally based research and demonstration and more effective transfer of information. These strategies would still likely achieve little, however, without the commitment of government agencies at all levels. Presently, the need for cooperation and coordination of effort possesses little value. The incentive to compete among agencies and individuals clearly outweighs those supporting coordination of effort. What is needed is a strong commitment at all levels of government to the notion that the service needs of severely handicapped citizens can be addressed only through cooperative goals and strategies."
--Robert Bruininks, et al

"The employment initiative for adults with disabilities is not a recent phenomena. Indeed, it has been the focus of the state-federal rehabilitation system since 1920. What is different, is the emphasis on transitioning to maximize the likelihood that the adolescent with a disability will become the adult with a job. Another new emphasis is the supported work model and its variants for severely disabled adults who would traditionally be considered ineligible for vocational rehabilitation services because the feasibility of gainful employment is remote. Now rehabilitation, whose developmentally disabled catchment population was the middle range of special educaton graduates (those who were higher functioning had no need for services; the lower functioning ones were not eligible for it), is being asked to stretch those lower population boundaries and sweep in a wider eligible population."
--Marita M. Danek

"Although market place reality for the nonhandicapped worker as well as the worker with a disability often involves high-turnover jobs which are vulnerable to economic turn down, Kiernan again hinted at a strategy that needs to be addressed, i.e., the market places as a market, segmenting the market, and targeting the market to acquire the best results."**--Carl V. Puleo**

"The major contribution of the paper of Kiernan is the **Pathways to Employment model.** This model focuses not on job placements, but on the effects of moving the individual into an employment status. This model describes a sequence of stages which a disabled person goes through. A special strength of the Pathways model is the focus on individual economic self-sufficiency, not only a specific type of job placement. I believe this model has enormous validity across different handicapping conditions; once it becomes more streamlined and gains greater national visibility in the literature, it will be adopted by many state policy planners.
Paul Wehman

"The expansion of the focus upon employment for all persons with disabilities will mandate that there be a redefinition of the industry/rehabilitation partnership. To train in dividuals for what is believed to be a need in industry without first documenting the need may lead rehabilitation programs to prepare individuals who will be ill equipped for entering the world of work. The concept of selling must be replaced by one of marketing where the assumption is not that 'we know what is needed' but that we will find out what is needed in the employment field and train toward that actual need. A true partnership where rehabilitation is a resource to industry will serve the purpose of matching the individual and the employment environment so that productivity is enhanced."
--Willaim E. Kiernan

"Vocational Rehabilitation, in particular, has the unique capacity to orchestrate the provision of transitional services between school and adult service delivery programs. Important to this consideration is that personnel in vocational rehabilitation may be the catalyst in bringing about appropriate transitional employment services. As previously indentified in our history, we already have a service delivery system in place. There are many skilled and talented individuals serving in this system, and the existing relationships between these individuals may prove to be a critical element in the establishment of a continuum of services from school to work."
--Marvin L. Tooman

"It seems to me that professionals are very important people to parents who have lost a significant dream, that dream of having 'The Perfect Child.' During this initial reaction a professional will play an important role in providing attentiveness and empathy to the parents. The first professional that is utilized will often times become a 'Friend,' creating a close bond between parent and professional. That professional should remain a part of the team indefinitely. These early bondings can be invaluable in the years ahead."
--Allen R. Searles

"Mr. Kiernan (in Chapter 6) appears to have captured all the varied methods of transition to the workplace for disabled individuals and groups. This paper would clearly define most options to participants in the system from both the employment-employee side and the employer side. He just touched the surface of one problem which crops up in most state rehabilitation programs that I am familiar with. That is, that little transition is sought until the disabled student finishes high school -- often, too late to plan a transition program. We need to find ways of attracting our disabled students in high school to the vocational rehabilitation resources already available.
--Elizabeth Dempsey

Acknowledgements

The Mary E. Switzer Memorial Seminar and the monograph of the proceedings were made possible by a great many people and their organizations dedicated to the independence and rehabilitation of persons with disabilities. It should be noted that funds were initially raised by a special committee of the National Rehabilitation Association (NRA) known as the Switzer Memorial Fund Committee, which was guided by Mrs. Olive K. Bannister.

Thanks are expressed to all who played some part in the planning and implementation of this memorial tribute to Mary E. Switzer. Special appreciation is expressed to the following persons:

The Switzer Memorial Committee members: Betty Hedgeman, Edwin Opheim, Richard Switzer, Steve Zimmerman, Joan T. Barker, and David Mills.

The Switzer Planning Committee for this seminar, whose names are listed in this monograph.

David Mills, Executive Director and his fine staff for constant support and kindness with numerous details. Richard Dietl for his work on this monograph and the numerous aspects that he so ably handled.

Special appreciation is expressed to the sponsors of the seminar (noted at the beginning of this monograph). They have our sincere thanks for helping to keep this living tribute to Mary Switzer alive for another year. Finally, thanks go to the gracious host of this year's program, Gallaudet College in Washington, D.C. and its President Jerry Lee and the many staff members who did so much to insure the success of the seminar. Appreciation is extended, of course, to the 20 excellent Switzer Scholars, for their time and expertise in making the seminar a memorable one.

It is the sincere hope of the Switzer Memoral Committee that the monograph of the Tenth Switzer Memorial Seminar will be used to enhance the services and understanding of youth preparing for one of the most significant passages in their lives, **the transition to work and independence.**

Switzer Scholar Tooman

Chapter One

An Historical Background of Transitional Employment Programs and a Perspective on the Future

By Marvin L. Tooman

One way to consider the history of transition is to look at our own experience with transition. At fourteen years of age I took my first paying job outside of my home. Following in the "footsteps" of my brother, I secured a parttime job as a bellboy in a hotel in our local community. Having grown up on a farm, the hotel was a totally new experience. I can confidently acknowledge that my knowledge of life grew dramatically during my short three month tenure in our local hotel. My first transitional experience to the "world of work" was somewhat shocking, but it did suggest to me that I had much more to learn and that a lot of that learning would not take place within the four walls of a school classroom.

A short time ago, during a discussion of transitional employment for students with disabilities, I asked a group of high school guidance counselors to think back to their first paying job outside of the home. While they were thinking about this job, I asked them to raise their hand if, at the time of this first employment, they were between the ages of 14 and 16, 16 and 18, 18 and 20, or 21 and over. That short nonscientific survey gave evidence, I believe, of some important information about transition. I found that approximately two-thirds of the group had obtained employment outside of the home by the time they were 18 years of age. Further, all but one of the remaining counselors had obtained employment before their 21st birthday. To my knowledge, none of the counselors present in this assembly had a disability.

The purpose of this little exercise was to illustrate that we have "transition gap". By definition, -- that is my definition -- a transition gap is the difference in time between when those of us who are temporarily able bodied first go to work and when persons with disabilities first go to work. In many respects, this seminar is seeking to reduce and to eventually eliminate this transition gap.

To insure that these counselors had a good understanding of their own transitional experience, I asked them why they took their first job outside of the home. Not wanting to become too peronsal, I suggested a few reasons. They were:

-- *Your parents told you to;*
-- *To get spending money;*
-- *To save money to buy a car;*
-- *To save money to buy clothes, or a specific article of clothing;*
--*To get out of the house;*
--*To save money for college; or*
--*To take care of the basic expenses of living, such as groceries and housing.*

There obviously are more reasons for taking a job outside of the home, but it seemed, nonverbally, that most of the counselors in the group could identify with one or more of my suggestions.

My ultimate purpose in this little exercise with these counselors was to have them transpose their feelings and emotions concerning their first job to what a young person with a severe disability might feel or sense in a similar situation. I asked them to imagine that they were a young person with a severe disability. It didn't matter what disability they had. It could have been anything: blindness, cerebral palsy, mental retardation, a physical deformation, or perhaps some combination of disabilities.

While they had this image, I asked them to also imagine that they had obtained their first job, and this job paid the same or perhaps a little more than the jobs of their classmates. They were to report to work the next day at 4:00 p.m. after school. I asked them to dwell a few moments on their feelings and emotions concerning this important event. I suggested that they might be anxious or nervous ... but that undoubtedly they would be very happy, perhaps even joyful. To assist in capturing the emotion of joy, I shared a few brief quotes:

"Joys are our wings; sorrows our spurs" -- *Richter;*

"Joy is not in things; it is in us" -- *Wagner;* and

"Joy is the sweet voice, joy the luminous cloud, we in ourselves rejoice-- *Schiller, A Hymn to Joy.*

This discussion of transition may take us into such things as cooperative agreements, model programs, disincentives and the cost effectiveness of moving persons with disabilities into employment, but while we are discussing these issues, we must observe and be sensitive to the human emotions and personal needs of those that we're seeking to serve. Our own anxieties, apprehensions and joys may be, for us, a keystone in reaching out in service to youth with disabilities who are in or are approaching transition to work and independence.

Lessons Learned and Lost, Or "Why Can't We Do It Like We Did Before?"

To a great extent, transition as we are dealing with it in this seminar, is representive of the educational and rehabilitation programs that extend back into the 1950's. My discussion with educators and rehabilitation providers throughout the country suggests that many of these people may be experiencing a case of *deja vu.* As we consider our own history, I believe we can firmly establish that transition DID exist before the 1980's. In fact, many people claim that the informal cooperative efforts of the 1950's were more representative of transition than many of the programs that we have today. And I must comment that as I spoke with these professionals there was fervor and emotion in their voices. As I interviewed these people, I sensed both a degree of pride and frustration as they considered my questions -- pride that a concept that they had fostered and developed in the 1950's and 60's is now, seemingly, coming into fruition and frustation that the concept of transition is too frequently being viewed as being totally new, unique and innovative.

In many respects, I've been extremely fortunate to be able to cross back and forth between education and rehabilitation and consider the history of both. In doing so, I've seen and studied a number of programs that have a remarkable similarity to what we call transitional employment. For instance, cooperative education, distributive education, industrial education, and work-study programs all contain elements of what we look for in a good transitional program. The career education movement of the '70's renewed our appreciation for the importance of work in our daily lives. I'm reminded of Professor Kenneth Hoyt's famous definition of career education. It is:

> *"The total effort of public education and the community aimed at helping all individuals to become familiar with the work values of a work-oriented society, to integrate these values into their personal value system, and to implement these values into their personal lives in such a way that work becomes possible, meaningful and satisfying to each individual" (Phelps & Lutz, 1977).*

Hoyt shared this definition in 1972, and in so many ways thousands of educators and rehabilitation providers across the country are grappling with how they can apply that same definition to their severely disabled students and clients. Perhaps this, too, is an illustration of the "transition gap" that I referred to earlier. Twelve years after Hoyt pronounced the importance of work for the individual, the President's Committee on the Employment of the Handicapped (PCEH) estimated that each year, of the 650,000 youths with disabilities who leave high school, either by graduation or age ineligibility, only 21% become fully employed.

Before we move on, let's ramble a little bit more through our history in education and rehabilitation. In 1906, the City of Cincinnati, Ohio, organized the first formal work-experience cooperative education program (Knowles, 1971). Over the years, the benefits of cooperative education became quite evident. They are:

a. School course work and real world experiences are most closely related;
b. Student's motivation increases;
c. Students develop a greater sense of responsibility, greater dependence on their own judgments, and increased maturity;
d. Students gain a greater understanding of other people and develop better human relations skills; and
e. As they become oriented to the world of work, students obtain knowledge about career opportunities and the requirements for being successful (Wilson, 1974).

Paul Wehman (Switzer Scholar, 1985), a noted authority on transitional employment and supported work, has identified a number of benefits relating to the employment of persons with severe disabilities. A few of these are:

a. The integration of persons with disabilities with their nondisabled peers offers them the opportunity to develop and maintain new social and vocational skills;
b. Growth and advancement within one's employment can be a motivation to higher levels of performance; and
c. Through competitive employment, a person with a disability may normalize their life (Wehman, 1981).

There are, of course, many more benefits for both cooperative education and the employment of persons with severe disabilities through transitional employment programs. And we shouldn't be too surprised at the similarity of benefits between these two programs. Should we expect that the experiential learning of persons with severe disabilities should be any less than that of those who are temporarily able bodied? Unfortuantely, the present effort to move learning for persons with severe disabilities out of the classroom, and/or rehabilitation facility and into the community is, as we compare it with the cooperative education movement, another example of the "transition gap."

To further illustrate the benefits of these programs out of our past, we can take a brief look at Distributive Education. Distributive Education or Marketing Education, as it is now called, is a competency-based instructional program providing specialized training in marketing, management, and entrepreneurship. The primary intent of the program is to prepare students for:

a. Employment in marketing and management occupations;
b. Continuing education and training; and
c. Business ownership and/or managerial responsibilities (marketing).

Experiential learning is a significant part of marketing education, and instructors become placement agents for their students. Program material designed for employers identifies how students can address the human resource needs of employers. For example, the following suggest what a training sponsor (employer) can expect from a marketing student:

a. An honest day's work;
b. A minimum of absences;
c. Punctuality;'
d. Loyalty, pride of employment;
e. Willingness to prepare for a job ahead;
f. A sense of responsibility;
g. Integrity;
h. Initiative; and
i. Enthusiasm (Charney, 1977).

Gopal Pati, in **Managing and Employing the Handicapped: The Untapped Potential,** identifies for employers what can be expected from handicapped people. They are:

a. Reliable;
b. Competent;
c. Highly motivated;
d. Personally independent (Pati & Adkins, 1981).

A good degree of interchangeability exists between Pati's rationale for the employment of the handicapped and the marketing instructor's placement efforts for his/her students. Similar comparisons can be made with world-study program and in distributive education programs.

It seemed that for a period of time, in the late '60's and early '70's, that programs for students with disabilities were going to capitalize on the earlier experiences with cooperative education and work-study programs.

"The Local Education Agency (LEA) -- Vocational Rehabilitation (VR) -- Special Education (SE): High School Cooperative Work/Study Programs swept the nation like prairie wildfire throughout the '60's and the first half of the '70's; due, in main, to the third party funding formula approved by the Rehabilitation Services Administration (RSA)" (Hostetter, 1985).

Third party funding allowed local school districts (county boards, or area education agencies) to underwrite a portion of the cost of a vocational rehabilitation counselor who served a specific school population. As vocational rehabilitation counselors began serving in close coordination with their educational counterparts, students with disabilities became the central focus of a combined service delivery system.

From 1961 to 1977, cooperative programs drew a great deal of attention and spasmodic progress in service to students with disabilities. Unfortunately, the "seeds of discontent" were planted at the same time the third party funding program first got started. With little guidance and direction from Washington, local control problems began to develop. "Turfdom" issues became evident, and the partnerships between LEA's, VR and SE were put to the test. With a few exceptions, the cooperative arrangements were unable to sustain themselves, and the focus of attention shifted from students with disabilities to the protection of individual agencies and programs.

While the problem of "turfdom" can effectively conclude most any cooperative agreement, there were a number of other contributing factors that led to the third-party funding program's demise:

a. First, the pre-service training curriculum for educators and rehabilitation providers differed dramatically. Rehabilitation education programs in the '60's and early '70's generally focused more on counseling than on job development and job placement (Usdane, 1976). Subsequently, the expectations of educators were frequently crushed as they saw their rehabilitation partners concentrating on those students with strong academic potential versus those that needed a job.

b. Second, there was no concerted effort to provide combined inservice training (Hostetter, 1985). Both educators and rehabilitation service providers performed their jobs with what they brought into it. There was little opportunity to gain a better understanding of what the other person's job was all about; and finally,

c. There was no concerted effort to administratively deal with problem resolution. Local problems or issues many times became the "death knell" to local cooperative efforts. It wasn't unusual to find an outstanding cooperative effort in one part of a state and a failure in another part of that same state.

Combined with these local problems and concerns, a number of national events seemed to accelerate the move toward disengagement of local cooperative efforts. For educators, P.L. 94-142 redefined their requirements for serving students with disabilities. Educational administrators were given more responsibilities and resources to see to the needs of students with disabilities. With these new requirements, educators were seemingly asked to do it all, and there was little motive to insure that cooperative efforts were in place with adult service delivery programs. In those cases where local funding was contributed for cooperative efforts, there was a desire to recall those funds. In many situations, where there had been a problem, educators felt that they could do it better themselves.

So, too, did rehabilitation administrators begin to find reasons to refocus their own resources. Local rehabilitation supervisors began having problems with inequities in caseload management. VR counselors placed in the schools generally had a much smaller caseload than those counselors with a general caseload. Local supervisors also, on occasion, felt that they lacked control or authority over the VR counselor assigned to the school. When, in the mid-to-late '70's, the VR growth and expansion began to subside, there was a general call for a more equitable redistribution of staffing assignments. As word of VR state agency discontent and alleged program abuses filtered to the Rehabilitation Services Administration, there were surveys and inquiries into VR's involvement in third-party funding programs. These inequities, under the direction of the Government Accounting Office (GAO), culminated in 1978 with a Program Instruction Memorandum by then RSA Commissioner Humphreys to cease and desist from third-party programs involving LEA's (Department of Health, Education and Welfare, 1978). This Program Instruction Memorandum was rescinded in August, 1979. However, the effect of the memorandum had already been established.

At approximately the same time that the then Commissioner Humphreys was issuing his cease and desist order, Congress was passing the 1978 Amendments to P.L. 93-112 (The Rehabilitation Act). A portion of these amendments specified that state plans include provision for establishment of cooperative relationships among vocational rehabilitation, special education, and vocational education (11th Institute of Rehabilitation Issues, 1984). Even though Commissioner Humphreys issued, in 1979, Program Instruction Memorandum (Department of Health, Education and Welfare, 1979) #RSA-PI-79-25 to clarify RSA Policy between such programs as vocational education, special education, and vocational rehabilitation, actual cooperative experiences had begun to deteriorate. There may have been, and perhaps continues to be, many interagency agreements within state government. However, these agreements have not generally been successful in the establishment of the continuum of services from school to work for students with disabilities.

It seems ironic that P.L. 94-142, the law that revolutionalized services to students with disabilities, in part, **contributed to the disengagement of cooperative efforts between LEA's SE's, and VR.** Of course, there were many other contributing factors to this disengagement, some of which have been identified in this paper. Perhaps the most damaging result of this bitter experience in cooperative programs is the fact that many of the VR managers and educational administrators at the time of the disengagement are now in senior administrator or executive positions within their respective organizations. Is it any wonder that we are hesitant if not reluctant to reenter a situation where our feelings, emotions, and pride were symbolically bound by a program that, in retrospect, was doomed from the beginning. It's much easier to nostalgically look back and say how good it was or could have been than to aggressively draw from our experiences and pursue a course that will enable us to refocus our attention on students with disabilities.

Transition from the Perspective of the 1980's

The topic of transition has received a great deal of attention in recent months. Many within the rehabilitation profession have tired of the subject and have concluded that the recent emphasis on transition is a fabrication of a group of folks in Washington or researchers hoping to sell a few books. Others are quick to point out that the concept is representative of the rehabilitation process and that we've been doing this over the last several decades. Rehabilitation providers have been heard to say, "We've been doing this for years!" For these people, transition is a catchy word that has had a lot of hype, and will fade as rapidly as it came to the forefront. It seems that many rehabilitation providers are intending to wait through the transition movement so they can return to business as usual.

Unfortunately, those who are waiting to see this initiative fade are going to be disappointed. Fortunately, for those committed to the elimination of the transition gap, transition is here to stay. In many respects, the transition that we are dealing with today is here due more to our history than to any person or persons within the Washington bureaucracy. The Vocational Education Act of 1963, the Civil Rights movement of the '60's, the Rehabilitation Act of 1973, P.L.'s 94-142 and 98-199, the Rehabilitation Amendments of 1978, and now the Perkins Vocational Education Act have all contributed to the conditions which caused the current movement for transition to develop and to mature. We can give Thomas Bellamy, Richard Melia, Paul Wehman, and many others credit for reawakening our nation to the current need for transition. Additionally, we can acknowledge and appreciate both research from the past (Hunter and Zuger, 1979) and the present (Wehman and Hill, 1985) for the evidence as to the worthiness of transition. Much of this research has also contributed to the development of new techniques for moving persons with disabilities into productive and profitable employment. However, it is the need of the hundreds of thousands of young people with disabilities that are coming through our systems that demands our attention to transition.

Perhaps the best way to "capture" transition from the perspective of the '80's would be to sample the feelings and attitudes of educators and rehabilitation providers that are serving students with disabilities who are in transition. The following observations come from rehabilitation practitioners and educators that are serving students with disabilities.

- *School personnel look to vocational rehabilitation as a place to send students for assignment to sheltered workshops and work activity centers. Special education personnel have built in the past and continue to build tremendous amounts of anger as they see the fruits of their labors essentially going down the tubes.*
- *Vocational rehabilitation counselors and administrators talk about the inappropriate expectation of school personnel. Comments are made that special education personnel haven't equipped their students for the real world. Statements have been made by VR people that schools only refer to vocational rehabilitation those that they can't place themselves.*
- *School personnel talk about giving up on rehabilitation. They're talking about developing operating systems that don't include vocational rehabilitation. They indicate that they've tried so many times over the years to work with vocational rehabilitation, but they keep getting rebuffed.*
- *Vocational Rehabilitation profesionals have noted that schools have made tremendous improvement in behavior and vocational planning for their students, but that doesn't necessarily mean that they will be able to be competitvely employed. Personnel within vocational rehabilitation recognize that school people are angry with VR, but this anger is only a result of a system that has failed. We all should recognize that vocational rehabilitation is at the end of the line within the educational system, and many of the deficiencies of that system are shifted off onto vocational rehabilitation.*

A concluding statement by an anonymous special educator may capture the feeling of many school people across the country. "In a sense we're going to count vocational rehabilitation out. For all practical purposes, we're looking for other alternatives. The bottom line for us is employment."

The idea that vocational rehabilitation may be dealt out of the system is very real. In 1984, Dr. Jean Elder, Commissioner of Developmental Disabilities, told how she was going to be placing the developmentally disabled utilizing vocational rehabilitation money. She stated again and again how people with developmental disabilities have failed to utilize vocational rehabilitation (Elder, 1984). The implication here is, of course, that in turn vocational rehabilitation has failed these persons.

Within the perspective of the '80's, if things continue as they are, the beginning of the end of vocational rehabilitation may be in sight. Seminars and initiatives on transitional employment can yet illustrate the need for cooperative programming. Special Education, Vocational Education, and Vocational Rehabilitation must show how, together, they have the capacity and capability of cooperatively working together to serve the needs of students who are in transition.

The vocational rehabilitation shortcomings that Dr. Elder referred to have the potential of suggesting that a new service delivery system needs to be formed around the employment needs of the developmentally disabled. The resources for any new service delivery program most likely, in today's economy, would be drawn from existing programs that have a questionable record. Unless the need for cooperative relationships in servicing students with disabilities is appropriately addressed and served, any reorganization of the traditional service delivery programs would be more like rearranging the deck chairs on the Titanic.

Vocational Rehabilitation, in particular, has the unique capacity to orchestrate the provision of transitional services between school and adult service delivery programs. Important fo this consideration is that personnel in vocational rehabilitation may be the catalyst in bringing about appropriate transitional employment services. As previously identified in our history, we already have a service delivery system in place. There are many skilled and talented individuals serving in this system, and the existing relationships between these individuals may prove to be a critical element in the establishment of a continuum of services from school to work.

If we are to be successful in the provision of transition services, it will be necessary for all of us to confidently identify that **our common turf is the student with a disability and that our primary system and purpose is to see that student successfully through transition and into productive and suitable employment.** Tom Peters, in his book **In Search of Excellence,** has identified that "any great organization owes its resiliency not to its form of organization or administrative skills, but to the power of beliefs and the appeal these beliefs have for its people" (Peters and Waterman, 1982). Peters went on to identify that virtually all of the better performing companies, within his survey, had a well defined set of guiding beliefs.

It is time now for us to develop our own belief that we can successfully place thousands of students with severe disabilities into productive and competitive employment. To aid in this belief, we can look to the track records of exemplary cooperative programs around the country and to the research findings from several university research and development programs. Perhaps best known of the research and development efforts is the work of Paul Wehman and his associates at the Rehabilitation Research and Training Center at Virginia Commonwealth University. Readings from this program familiarizes us with such terms as:

- *functional curriculum;*
- *community-based instruction;*
- *integrated school services; and*
- *job-site training (Wehman and Hill, 1985).*

The name of Thomas Bellamy and the University of Oregon should be familiar to those dedicated to transition. They have been prolific in supplying the profession with data and evidence of the success of students with severe disabilities in employment (Bellamy and Wilcox, 1981).

Moving from research to practice, the consulting firm of Harold Russell Associates (HRA), through a contract with the U.S. Department of Education, provided detailed information on exemplary cooperative programs for transition from school to work. This report identified how effective transition programs, involving extensive cooperation between service programs, could be implemented and refined in differing geo-political circumstances. The HRA study should be a companion document to the other research data on transition, and should be referenced by developing transition projects.

Occasionally, in a new movement or program revitalization, there is confusion and misunderstanding as to the meaning of particular terms, usages, or program goals. There is an inherent danger that a national movement could be stalled or stopped under such circumstances. Fortunately, the U.S. Department of Education, Office of Special Education and Rehabilitation Services (OSERS), under the direction of Assistant Secretary Madeline Will, conceptualized a transition model (Will, 1984). Those employment services associated with the model were identified and defined for replication. We have subsequently been able to "lock-in" the terms of generic or regular employment services, time-limited employment services, and on-going employment services commonly known as supported work.

A quick review of transition in the '80's finds that we have a well-defined movement with supportive research and exemplary experiences that is gradually building in momentum. The resistance to this movement comes from a history of suspicion, distrust, isolation, and the inability to focus on the employment needs of students with disabilities. While there have been numerous pieces of legislation enhancing education and rehabilitation services, there has been little need to develop and sustain cooperative programming. In fact, these legislative efforts and the accompanying commitment of resources have increased the competition between service programs.

During the period of growth in the '60's and '70's, administrators in both education and rehabilitation sought to build up their own programs with little need to establish linkages with other service providers. Now that our resources are becoming increasingly finite, there is a tendency to hang on to what we've got. In essence, we're saying, "Hold on at any cost. When you've got holes in the system, fill them the best way you can. Just try to maintain the organizational system. Things have got to get better. We'll get well here in a few years, perhaps with the next administration." Administrators may possess a degree of personal ownerhship and pride over their programs, and any attempt to establish linkages that would in any way alter their image or identity has the potential to be viewed as a personal defeat. This represents an entrenchment mentality, and the old cliche of "pride goeth before the fall" seems to be especially appropriate.

Perhaps as we move on through the '80's, our adversities may cause us to ultimately rejoice as we, through necessity, reach out in partnership with the common belief that students with severe disabilities represent an underutilized human resource of great potential value to employers and to our country.

Transition of the Future

A review of the history of transition and a quick look at transition in the '80's suggests that we have a rocky road ahead for us, but that we do have the tools and the knowledge to smooth that road and to reduce and hopefully eliminate the transition gap that was previously identified. As with most disciplines, if we attend to our history, we can possibly avoid a few mistakes and, in some cases, we can increase our creativity.

An understanding of our history with transitional employment may provide evidence for us to prescribe activities and/or special initiatives for the future. The following prescribed programs and activities do not represent a comprehensive list that will insure the successful establishment of a continuum of services across our nation. They are, however, critical of a continued development and refinement of the transitional employment initiative. A void in any one of these programs or activities may cause the delivery of services to become or continue to be fragmented and isolated. They are:

a. Cooperative Education;
b. Life Long Learning;
c. Marketing; and
d. Parent Education.

Cooperative Education

Cooperative Education may, as it has for students in general, offer improved access to employment for students with disabilities. Recently a meeting with IBM executives representing their General Products Division gave evidence that a full 50% of professional hires in recent years were former cooperative education students. In addition, they indicated that IBM is working toward an even greater percentage of coop conversions to permanent employees in the near future (Abita, 1985).

Cooperative Education initiated as the secondary level should offer students with disabilities an introdisciplinary approach to vocational programming. Planned and directed by a team of vocational educators, special educators and vocational rehabilitation counselors, a cooperative education program should mesh classroom instruction with on-the-job training across all career clusters. Such a program shares with the home, community, and school the responsibility of helping a student gain the knowledge, skills and attitude necessary to become a useful, productive person.

While the number of experiential learning settings for students with disabilities has grown, they have not become a regular part of the transitional process. We will know that we've reduced the transition gap when we regularly see: a stock clerk in the local supermarket who is mentally retarded; a checker who runs the laser cash register who is blind; and a cashier at McDonald's who has spina bifida.

Through experiential programs such as

cooperative education, business and industry sectors can forge a partnership that provides schools and rehabilitation agencies with opportunities to expand their program resources without a corresponding increase in expenditures. Institutional managers, corporate executives, union leaders, and public officials concerned with economic development share a common interest in improving cooperation between schools, business/industry, and rehabilitation (Clark, 1984).

Life Long Learning

Life Long Learning will necessitate that students with disabilities have a place within business and industry to insure that this personal growth and development continues. As young persons with disabilities find their places in productive and profitable employment, they will also find that they are along side their nondisabled peers. Soon they will, through effective transitional employment, experience the ultimate aspect of integration. It must be understood, however, that if persons with disabilities are to both sustain themselves and to grow within their employment, they will need to recognize and participate in life long learning.

The National Commission on Excellence in Education spoke, in its "Report to the Nation" (1983), of a need to create a Learning Society. The Commission acknowledged that the heart of a learning society are those educational opportunities that extend far beyond the traditional institutions of learning. Our schools and colleges are no longer recognized as the only locations for educational opportunities. These opportunities extend into homes and workplaces. They literally extend into every place where the individual can develop and mature in life and work.

Schools and other educational institutions were and continue to be responsible for the integration of youth with disabilities into the classroom, as initially mandated in P.L. 94-142. However, it will be the businesses and industries of today and tomorrow that have the responsibility to see that those same young people with disabilities continue their educational development into adulthood and through their working life. The mandate for businesses and industries to provide life-long learning opportunities for persons with disabilities will not likely come from a law or some sense of duty, but from the belief that persons who are disabled represent a valuable human resource that must be maintained and renewed so that they may continue to be valuable to both business and/or industry and to society in general.

Conclusion

This review of our experiences in transition suggests that we are sometimes dealing with a controversial subject that can invoke a great deal of feeling and emotion. Progress comes slowly in such an environment, but progress is being made. A statement by John F. Kennedy captures, I believe, the essence of our transitional employment movement.

> *"My experience in government is that when things are non-controversial, beautifully coordinated, and all the rest ... it must be that there is not much going on!"*

As far as transitional employment is concerned, there is a lot going on.

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Excerpts of Reviews and Comments

The following are excerpts of reviews, comments, and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as it relates to the content of Chapter One by Marvin L. Tooman.

In regard to Dr. Tooman's reference to the interagency agreements established in prior years, I submit that, in many instances, the 'so-called' transition efforts developed in the 1950's and '60's represented only **dollar resource transfers.** Hopefully, in this revitalized transition movement we are more concerned with positive individual outcomes rather than a 'numbers' count.

Irregardless of the strides made in technological advances, we will continue to be a work-oriented society if for no other reason than the reality that societal values are aligned with academic, economic and social achievements/standings, and self esteem and self satisfaction. All of these variables are measured within established success standards. Further, I interpret the current efforts in transition not be to "move" learning for persons with severe disability out of the classroom and/or rehabilitation facility, but, rather, to extend the learning experience into the real world of community living and work experience. To suggest that education and rehabilitation facilities are not essential elements in this movement is, in my opinion, an erroneous assumption.

-- MIRIAM E. WALKER

Dr. Tooman has a unique perspective in developing this paper. As a national leader in the field, he commands respect from a wide range of rehabilitation professionals. He has generated several provocative thoughts in this paper. This review briefly highlights several of the more helpful comments as well as some constructive criticism.

I was very pleased to see Dr. Tooman's comments about the role of different disciplines in effecting change in current service systems. Specifically he aptly notes the perceptions and sterotypes which different professionals hold of each other; this is an excellent section which captures much of the turmoil and anxieties felt by people currently in the field.

I also was very impressed with how well the Administration on Developmental Disabilities' role was presented in this movement. Dr. Tooman accurately observes that state developmental disabilities councils will be increasing expectations among consumers thus placing even more pressure on vocational rehabilitation to serve this population. The focus on marketing needs was also very good.

Finally, I was happy to see that transition as a "fad" was discussed and rebutted. Yes, we have been through some of this movement before, but things have changed. This is the chance many professionals and parents have been waiting for and it is essential to take full advantage of it.

The major criticism I have is that it seems transition and employment were mingled too much together as if they are the same initiative. This has happened frequently and tends to confuse readers less familiar with the issues.

-- PAUL WEHMAN

It was a pleasure to read "An Historical Background of Transitional Employment Programs and a Perspective on the Future," by Dr. Tooman as it helped me stop and think about what has happened during my fifteen years in the vocational rehabilitation field. The transition of young people with disabilities from school to work is an "event" which most Americans take for granted and usually happens when an adolescent reaches age sixteen. Tooman reminds us that the transitional event is usually absent in the developmental process of adolescents who are disabled. Obviously the "event" of accepting the responsibility of part-time and summer employment is a critical step in the development of a work personality. I can recall when I went to work at age sixteen as a short-order cook in a 24 hour-a-day hamburger shop. It not only forced me to conform to a schedule, but more importantly thrust me into relating to adults in a work setting. Although the experience created anxiety, it eventually allowed me to gain the confidence that I could relate to adults as peers in a task oriented situation. A large number of the young people we see entering rehabilitation facilities have not been given the choices and/or opportunities to

access the world of work as early as possible. Without these early employment experiences, a young person is deprived of various **role models** which can help create a well developed and flexible **work personality.**

The three communities of business, education and vocational rehabilitation must continue to create formal communication and liaison relationships to offer innovative career planning for young people with disabilities.

-- ALLEN R. SEARLES

This excellent historical review provides the insight needed to appropriate development and initiation of strategies for the future. The programs and activities - Cooperative Education, Life Long Learning, Marketing and Parenting Education - identified as critical to the continued development and refinement of the transitional employment initiative are most appropriate.

However, I completed reading the paper somewhat disappointed in that specific strategies for enhancing transition in the future were not discussed. How do we really get past "turf" issues in developing cooperative programs? Who funds these? Any "turf" issues there? How do we transition if adequate funds are not available?

I would agree that **transition** is here to stay. Hopefully, leadership within the rehabilitation movement will be able to **creatively build upon experience of the past,** identify solutions to existing problems, implement these and educate the public to the benefits of their on-going financial support of these efforts. If the leadership is able to do this, a window of opportunity exists for significantly enhancing **rehabilitation service delivery** in this country. If not, the window could be closed for the last time.

-- AMOS SALES

The underlying theme in Dr. Tooman's paper is identifying the transition from school to work problem, i.e., **the Transition Gap,** and exploring the strategies needed to close the gap. His comparison of the able-bodied youth transition to work with that of individuals with disabilities does focus on the problem.

Tooman's sketch of the historical sequence of the concept of transitional programs makes a valid comparison between cooperative educational programs and our reformulated concept of transitional programming. The benefits of the former to the students involved parallels the benefits to youth with disabilities involved in transitional employment and supported work.

Rediscovery that successful work-oriented **programs of the past,** cooperative education, can be recast as a foundation for successful work oriented programs for persons with disabilities **for the future** was developed by the author.

The problem to be addressed is to see that our strategies involve the cooperative efforts of all segments of the environment who must **buy into** the concept if it is to work consistently and with success in the market place.

The author clearly identified other factors which require addressing and resolution if the system is to "heal itself" and be a vehicle and catalyst for supporting the efforts to effectively provide for the transition of youth with disabilities into meaningful work.

Tooman's affirmation that "transition is here to stay" is not merely optimistic conjecture. The ferment which has been generated from Washington, which we identify with OSER'S (Office of Special Education and Rehabilitative Services) and Madeline Will, Asst. Secretary of Education, surrounding transition and supported work and which has spread across the United States, has reawakened in us our **transitional heritage** which Tooman has highlighted.

Central to the author's theme of ensuring the success of the transitional employment movement, is his emphasis on the cooperative efforts of all parties, the identification of their common turf, and adherance to the common mission, i.e., "...see the students with disabilities through transition and into productive and suitable employment."

This paper raises an important question for discussion that calls for examination and solutions. Where and when should the business community become **partners** in this cooperative effort.?

Tooman rightly postulates an interdisciplinary team approach to vocational programming involving the vocational educator, special educator, and vocational counselor. I would add to that interdisciplinary team, the parent, student, and even most important, the **business person.** If we are placing on business the responsibility to employ persons with disabilities, and to also continue their educational development, then we must in partnership with business and industry develop the necessary strategies to effectively make this transitional process an ongoing and growing reality.

Tooman touched on this idea in his brief discussion on marketing. Obviously, the experts in marketing and its success lies primarily with the business sector -- all the more reason to become engaged with business in the **joint endeavor** to open the doors of work to an increasing number of youth with disabilities through the transitional and supported work approach.

-- CARL PULEO

Tooman indicates that discussions with educators and rehabilitation providers throughout the country suggest that many people may be experiencing a case of "deja vu." I agree that some of the transition issues we are dealing with today are representative of the educational and rehabilitation programs that extend back to the 1950's. However, I believe that Dr. Tooman could have stressed some of the contemporary issues which would indicate that today's transition **differs dramatically** from previous experiences.

Probably the most frequently asked question in special education today is what will happen to the more severely handicapped students when they are no longer eligible for special education services. Parents and professionals are learning that the only "zero-reject" mandate for services is in public education. Promises for a continuum of community-based services for all handicapped individuals have, to a great extent, gone unfulfilled for the adult population.

Transition from school to adult and working life should be considered a reaffirmation of **full services** for all handicapped individuals. I view the transition from school to work as an established goal for full employment for all handicapped individuals. Viewing transition as a full employment goal necessitates coordination among all service providers to ensure that programs, services, and support are available to assist handicapped individuals obtain and maintain employment.

-- WILLIAM HALLORAN

As Tooman points out, varous professional groups have, for years, recognized the need for, and importance of, transition. However, what is important about the recent refocusing on the transition issue is that it is oriented toward severely disabled young adults who were largely ignored in earlier transition projects, partly because many of these individuals were not even permitted to attend school. These are individuals for whom employment was not even considered feasible until recent years. These individuals will sometimes require not just transitional services, but long-term services in order to continue working, to live in the community, and to take part in community activities.

Tooman argues that vocational rehabilitation agencies have a unique capacity to orchestrate the provision of transitional services between school and adult service delivery programs. I would argue that success with these severely disabled young adults will often require strong collaboration between many agencies, vocational rehabilitation agencies, developmental disabilities agencies, mental health agencies, and others. Which agency will actually have the lead role in orchestrating a transition plan will probably depend upon the needs of the disabled student and will vary from state-to-state. Most states are now working out methods of coordinating the efforts of the different agencies. We should worry less about which agency has a lead role, and more about developing ways for the agencies to **cooperate in transition strategies.**

-- RONALD W. CONLEY

As expressed in this paper, transition is not new but a process that has been around for sometime, perhaps under other names, i.e., work-experience, cooperative education. The inclusion of the student with a disability largely depended on funding i.e., VR third party contracts, for some time there has been vocational education money set aside for the disabled student.

The definition "transition gap" is brought forth illustrating another example of why disabled youth may be having difficulty getting work.

Many of the key issues/problems within the transition process are discussed from the historical point of view. Are we going to dwell on history or are we going to move ahead?

Further Discussion:

1. There may be a "career choice gap." Consider the number of career choices a temporarily able-bodied student or youth makes. A student or youth is expected (directly or implied) to make one vocational choice. This is especially true of vocational rehabilitation's (VR's) policy to provide services to clients at the lowest entry level, rather than seeing a continuum or progression of "bus boy" to cashier to chef, (the last requiring some formal training). If a youth with a disability changes jobs many times, he will be labeled "unstable" rather than **exploring** jobs.
2. Special education programs (18-21) need to work with community colleges for a transitional program of education.
3. Lifelong learning programs need to be expanded to provide educational/learning programs after employment. What happens to the worker who is developmentally disabled and wants to learn to read, or expand general social opportunities?
4. The new education programs at the university level specializes in transition programs.
5. Special education classes are usually small, the student may not be challenged to excel unless

mainstreamed, then he may not be prepared to function in a large class. Special education instructors see progress in relationship to others in the class rather than progress as measured in the mainstreamed class.

-- FLORENCE R. CURNUTT

Tooman's historical review of transitional programs certainly did provide a sense of deja vu! Those of us who were "there" in the 60's remember the excitement of "school units" cropping up within public schools but staffed by rehabilitation counselors. The "school" counselors were also the envy of those of us rehabilitation generalists who were held to the higher number game which escalated yearly.

Perhaps transition is merely old wine in new bottles - however, the label "transition" firmly affixed to the concept insures that it will remain in our vernacular. I suspect, to elaborate on Tooman's analysis of what happened to early attempts at transitioning, that Public Law 94-142 gave LEA's total authority over students with disabilities through age 21 and rehabilitation was happy to find an excuse to bow out: "Bye, call us if you need us!" In addition to the perception of "school" counselors as better off than the rank and file, there was the "lag time" between acceptance and closure that was often unacceptably long for an agency that must repeatedly justify itself through statistics.

As Tooman notes, special education folks are justifiably mad that the carefully crafted career education goal in their students' IEP (Individualized Education Plan) will oftentimes be disregarded by the VR counselor. But why not initially involve the VR counselor in the IEP development?

And if rehabbers feel the special ed folks are unrealistic, why don't they do some "in-service" education about local labor market conditions and employer expectations? For that matter, educate them about **rehabilitation requirements** and process. It is my experience that special ed personnel know very little about rehabilitation.

I disagree with Tooman that the end is near for vocational rehabilitation. Remember, developmentally disabled persons - the usual recipients of transitional services - were not the population that the rehabilitation system was originally designed to serve. Back in 1920, this system was devised to return the disabled soldier and worker to employment as quickly and efficiently as possible. There are still enough of these people who need services.

Would a separate VR system for developmentally disabled students better meet their needs? Perhaps if it eliminated eligibility requirements and time-limited services. Would/could the taxpayer support such a system? Only additional research into supported work and other innovative approaches to reduce dependence will tell us the answer.

Finally, Tooman hit upon one of my favorite themes: parent education is crucial. The parent is in for the long haul. A collaborative partnership with parents is the only way professionals can insure that the objectives so carefully developed in their IEP's and IWRP's (Idividualized Written Rehabilitation Plan) become a reality.

-- MARITA M. DANEK

SUMMARY OF RECOMMENDATIONS

The following is a summary of the recommendations and implications for action developed by the Switzer Scholars as they relate to the topics of Chapter One and Two. (The recorder was Miriam E. Walker).

Recent history (within the last 15 years) in special education and rehabilitation gives evidence that transitional employment services have been, on a sporadic basis, available to students with disabilities. However, professionals within these two service sectors have been unsuccessful in developing and establishing a continuum of services, from school to work and independence, for students with disabilities. Administrators have been forced to acknowledge that the conditions for the mid- and late-1980's have, and are, continuing to change so dramatically that immediate intervention must be initiated to the human potential, social integration and community adjustment of students with disabilities.

1. **Recommendations/Implications that would enhance service delivery:**
   - A. That rehabilitation, education, and other human service systems involved in transition services implement and maintain more accountable, outcome-oriented management and evaluating and improving transition service programs.
   - B. That client-based management information systems be develooed and implemented across all service organizations for planning purposes, monitoring, evaluating and improving transition service programs.
   - C. That employers be included and given a 'prominent' role in the transition program

design and implementation. Projects With Industry (PWI) type models which have demonstrated a high degree of success in placements are often those wherein business/industry leaders have assumed program 'leadership' roles and, consequently, have an investment and/or 'ownership' in the concept and design.

2. **Recommendations/Implications for policy or program development:**
    A. That a jointly funded, Federal interagency research and demonstration initiative be encouraged to examine the feasibility of maintaining active data collection on residential and community service programs, their clients and service outcomes.
    B. That interagency coordination and planning for transitional services establish specific roles and responsibilities for each service component, including the identification of points for each agency's intervention and responsibility.
    C. That individual service plans be developed through cooperative efforts of all appropriate agencies and programs at least two years before students with disabilities leave school.
    D. That existing resources for enhancing semi-independent living options and supported employment for disabled persons be more fully exploited

3. **Recommendations/Implications for training of staff, the general public, etc.:**
    A. That transition strategies be developed to address the career development and post-secondary educational and training needs of all disabled students, including those disabled persons classified as high achievers and academically gifted students.
    B. That competency-based management training programs be organzied and implemented by federal and state agencies for administrative personnel in local state agencies and programs.
    C. That greater emphasis be placed within current rehabilitation and special education training activities on policy and evaluation research on services and service outcomes. Included in this training focus should be information concerning cost benefit analysis and evaluation methodologies.

4. **Recommendations/Implications for needed research:**
    A. Ongoing longitudinal studies are needed that describe experiences, outcomes, and needs of (1) disabled students leaving school, (2) youth and adults who have been deinstitutionalized, and (3) disabled adults living with natural or adopted families. Such studies should address factors which relate or contribute to succesful and unsuccessful outcomes in community settings.
    B. That research be conducted to assess the different means for increasing cooperative., goal-oriented, programs while students are still involved in secondary level education. The dissemination of these research results would be of utmost importance to the field.
    C. That demonstration projects be supported to design and evaluate efforts to develop 'outcome' oriented management approaches in human service programs for youth with disabilities.
    D. There is a need to further explore through research and demonstration, the post-secondary needs of currently underserved disabled youth. Included in this population would be inner-city, disabled youth and disabled youth characterized as academically motivated.
    E. That research and demonstration program be encouraged and supported at the state and local levels to develop alternative reimbursement strategies which would eliminate existent barriers to transitional services imposed by regulations. Barriers identified which impede or prohibit the provision of employent or community-based services are: 1) the inability of service agendies to "pool" funds and/or other resources, and 2) lack of residential and/or transportation accommodations.

    F. That discretionary resources be allocated for the evaluation of the "best and most promising" transition practices and the translating of research results into practice. Priority projects may include: case management services; employment training and placement; funding incentives; reimbursement methods; client development programs; and, program monitoring systems.

    G. That research and demonstration projects be developed to assess the efficacy of using vouchers and/or contacts for client services in which funds would follow the client rather than the present system of reimbursement to service programs for disabled students leaving school. (This is a recommendation that careful evaluation of this alternative funding approach be undertaken and should not be construed as an endorsement of the process.)

5. **Recommendations/Implications for legislation -- Federal, State, local:**
   A. Transitional employment services will need to be available beyond an initial placement in subsidized or unsubsidized employment. It is recommended that business and industry will need to provide "life-long learning experiences" for their employees with disabilities in order to maintain productivity and profitability. A separate recommendation is that tax credits be provided where employers incur exceptional expenses for the provision of retraining and/or reasonable accommodations for persons with disabilities.
   B. That support be given to an increased level of State and local financial participation in providing for the transition and post-secondary service needs of disabled persons.
   C. That accountability measures be enacted to assure that persons with disabilities have equitable and appropriate access to JTPA (Job Training Patnership Act) resources.

Switzer
Scholar
Bruininks

Chapter Two

Facing New Challenges with Old Strategies: Needed Reform in Managing Adult Services for Disabled Citizens[1]

By Robert H. Bruininks*
K. Charlie Lakin
Bradley K. Hill

Approximately 25 years ago, a noted attorney titled a perceptive article on the challenge facing society and contemporary educational institutions, "Everything Nailed Down is Coming Up Loose" (Fishwick, 1963). This expression, taken from different context, aptly describes the current condition of adult services in the United States today for severely handicapped citizens and their families. Despite enormous gains in funding and more enlightened attitudes, services to disabled citizens are still managed through an incredibly complex maze of legal guidelines and archaic management strategies at every level of government. Recognition of this longstanding dilemma, often rediscovered annually, has consumed the attention of numerous conferences and the pages of extensive reports for much of the past 20 years. Yet our structures and strategies for managing human services have changed little during this period. They, in fact, appear to function poorly and with little coordination, at a time when integration of purpose and action are urgently required to address the service needs of disabled adults.

Efforts to achieve greater coordination of services to address the life long needs of people with disabilities has been a longstanding preoccupation of public policy. Over 20 years ago the President's Panel on Mental Retardation argued eloquently for establishing a continuum of services and a fixed point of referral (President's Panel on Mental Retardation, 1963). However, the issue of coordination among service programs has been given a renewed sense of urgency in the past several years. There are many diverse reasons for the even more pressing nature of this issue today. Within the past several years thousands of severely disabled youth have left special education programs to confront the vicissitudes of adult life. They have all too frequently confronted a reality of social isolation, little or no employment, low income for their daily needs and inadequate residential and other services.

Deficiencies in services for severely disabled youth and adults are particularly apparent in employment statistics from a number of recent studies (Halpern, Close & Nelson, 1986; Hasazi, Preakill, Gordon & Collins, 1982; Mithaug & Horiuchi, 1983; Wehman, Kregel & Barcus, 1985). Depending upon the study, the rates of unemployment and substantial underemployment among mildly and severely disabled youth and youth adults generally range from 50 to 75 percent. Although much of the existing data on employment in recent studies was gathered during a serious economic recession, the rates do reflect problems far in excess of those experienced by non-disabled age cohorts. The issues surrounding employment, however, represent just one of many service problems presently faced by adults with disabilities. Similar problems in availability and coordination of services could be cited in residential living, social and leisure opportunities, and transportation (Bruininks, Hill, Lakin, & White, 1985; Calkins, Walker, Bacon-Prue, Gibson, Martinson, & Offner, 1985; Fifield & Smith, 1985).

Concern about the lack of adult services for persons with serious disabilities has led to several major initiatives by the U.S. Congress, the Administration on Developmental Disabilities and the Office of Special Education and Rehabilitation Services (Elder, 1984; Will, 1984). The seriousness of these issues, particularly during the transition period from school to adult life, is also highlighted in revisions of the Developmental Disabilities Act of 1984 (Public Law 98-527) and in revisions of Public Law 94-142, the Education for Handicapped Children Amendments of 1984 (Public Law 98-199).

Reform in management of educational and other human services for people with severe disabilities represents a major national problem. It is a problem that cannot be solved today simply through the infusion of new fiscal resources, although vastly increased resources always make it easier to promote constructive change through developing new structures and strategies to overcome the inertia of old ones. Unfortunately, our national agenda and economy (at all levels) will not provide us with such a simple solution to the problems of unavailable and inadequate public services for disabled citizens.

It is the thesis of this paper that improvement of services for adults, particularly for those leaving organized school programs, cannot be realized without developing more effective strategies for implementing public policies and programs. This paper begins by discussing some pertinent recent history; it then analyzes barriers to improvement of services and suggests some modest ideas to promote change and reform.

Historical and Contemporary Factors

Life experiences of most handicapped people have changed dramatically in recent years. For handicapped citizens and their families, social advances have been reflected in a more progressive philosophy toward integrating handicapped people into society, recognizing and extending their legal rights, and substantially increasing public support for educational, residential, income maintenance, training, and other essential services. These changes have provided numerous alternatives to the segregated service models that were virtually the only options available not long ago. They have also created important challenges for the management of service programs.

Progressive social changes are often accompanied by unintended consequences. Despite positive growth in opportunity and acceptance of citizens with disabilities, difficult problems are still evident in programs available to them. With the decentralization of services from more concentrated institutional models, attempts to increase the social integration and family support for handicapped people have been thwarted by increasing fragmentation of responsibility among many varied agencies. The rapid progress of the past few decades, moreover, has not been without the intense conflict over purpose and strategy which invariably accompanies change in practices, in the level of involvement and responsibility of families, and in the roles of professional personnel.

Few events in our society have so radically transformed the lives of handicapped citizens as the public policies of deinstitutionalization of residential services and mainstreaming in educational programs. These policies, sharing common philosophical and legal principles, signify recent progress and, at the same time, have become symbolic markers of the many complex problems in assuring full opportunity for severely disabled people in our society.

Social Changes

The past decade saw a remarkable change in both the social perspective on the care and habilitation of severely disabled persons and in the funding made available to implement service programs. There were several highly related factors that promoted changes in society's response to severely disabled people. The most important of these are briefly discussed below.

Parent-consumer movement. The effect of parents as consumer-advocates for handicapped people has been felt since the end of the Second World War. One of the most influential parent-consumer groups has been the Association for Retarded Citizens (ARC). Begun in the late 1940s with about 40 parents and advocates for mentally retarded children, ARC has been particularly influential in the establishment of improved educational, residential, and support services for retarded people of all ages. The evolving advocacy of this organization has been highly influential in defining each decade's standards for programs serving handicapped persons. For example, in the 1950s ARC called for restrictions on the size of institutions; in the 1960s it assisted with establishing minimum standards for residential care facilities; in the 1970s it passed a resolution to recommend "residential facilities consisting of small living units, each replicating a normal home environment to the closest extent possible" and "that such residential facilities take absolute precedence over further capital investments in existing or new state institutions" (NARC, 1976, p. 3); and in the 1980s ARC is supporting legislation to shift Medicaid funding from large institutional settings to smaller living units in community environments.

Parents have been equally active in promoting educational and related services for handicapped children and youth. In addition to the ARC, parent groups like the National Society for Crippled Children, United Cerebral Palsy and, more recently, the Association for Children with Learning Disabilities have actively and politically pursued special education and related services for handicapped children and youth. In many instances, this was done with the concerted cooperation of professional groups like the Council for Exceptional Children, the American Association on Mental Deficiency, and the National Education Association. There has also been growing activism among severely handicapped people to function as their own advocates. One such self-advocacy group is "People First," originally a Canadian organization.

Civil rights movement. The great social movement in the 1960s to grant full civil rights to this nation's ethnic and racial minorities spread in the 1970s to other minorities including groups of handicapped people. In part this movement was related to the parent-consumer movement. But, in large measure, it went beyond mere advocacy for improved services, to publicizing the plight of severely handicapped individuals, and contending that the conditions of their treatment, in many specific instances, represented a deprivation of constitutional rights. The landmark decision in this movement was **Wyatt v. Stickney,** a decision that highlighted legal concern over treatment in residential facilities. In this 1972 Alabama case, in which the court ruled that mentally retarded people have a right to treatment in the "least restrictive" alternative:

> *Residents shall have a right to the least restrictive conditions necessary to achieve the purposes of habilitation. To this end, the institution shall make every attempt to move residents from: (a) more- to less-structured living; (b) larger to smaller facilities; (c) larger to smaller living units; (d) group to individual residence; (e) segregated from community to integrated into the community living; (f) dependent to independent living. (1972, p. 396)*

In the decade following **Wyatt,** a host of other court cases have approached issues related to the constitutional rights of severely handicapped people in residential, employment and educational services (Bradley, 1985; Laski, 1985).

While constitutional issues regarding services provided handicapped people have been raised frequently in recent years, the most important actions have been legislative. Most significant on the national level has been the passage of Public Law 94-142 (1975) and Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112), but states have also been extremely active in assuring the educational rights of their handicapped children, youth and adults.

Federal and state legislative activity. Following the Civil Rights Act of 1964, the constitutional interpretation of a number of federal and state court cases, mounting pressure from parents and advocates and a growing realization of the discriminatory treatment of handicapped people, the federal government passed two major pieces of legislation in the mid-1970s. The first of these was Section 504 of the Rehabilitation Act of 1973 which dealt with the issue of discrimination. The legislation stated that no handicapped person "shall solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance" (Sec. 84.4 [a]). The provisions of the Section 504 regulations required states to make efforts to remedy practices, avoid unnecessary segregation of services, and to modify programs so that they serve handicapped people with equal effectiveness.

The second major piece of legislation affecting handicapped children and youth was Public Law 94-142: The Education of All Handicapped Children Act of 1975. As noted in the legislation, the Act promises:

> *a free, appropriate education which emphasizes special education and related services [to handicapped children] designed to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected, to assist states and localities to provide for the education of all handicapped children and to assess and assure the effectiveness of efforts to educate handicapped children. (Sec. 601 [c]).*

This enabling legislation and its subsequent regulations specify that there be **no exclusion** of handicapped children from a **free, appropriate education**, as outlined in an **individualized educa-**

tion plan (IEP) based on a **nondiscriminatory evaluation,** with **parental** and **professional participation;** and which provides for placement in the **least restrictive setting** appropriate. Despite the fact that this federal legislation promised far more than it was willing to pay for, a 1981 report of the General Accounting Office concluded that in large measure these guarantees for severely handicapped children and youth have been realized (General Accounting Office, 1981).

Government advocacy. In addition to the substantial government initiated advocacy across local, state, and federal levels, there are also important advocacy and program development agencies nested within federal and state (and sometimes local) levels of government. These agencies are most visible at the federal level, where they exercise considerable influence on the policies and programs of the Department of Health and Human Services, Education, Housing and Urban Development, Transportation, and others.

Public exposes'. Another important influence in promoting socially integrated approaches to serving the needs of handicapped people has been numerous and potent exposes' on life in institutional settings. One of the first, and perhaps most important, arose from Robert Kennedy's unannounced tour of two New York state institutions two decades ago ("Where toys are locked away," 1965). Kennedy's visits were followed by Blatt and Kaplan's (1966) powerful photographic essay of a Christmas visit to a number of state institutions (1966). This volume and a **Look** magazine article containing many of the same photos focused national attention on the condition of state institutions (Blatt & Mangel, 1967). Another expose of enormous impact was Geraldo Rivera's videotaping of life in another New York state institution in the early 1970s. That video-essay **(Willowbrook: The Last Disgrace),** shown on local and national television, had a powerful impact on attitudes about state institutions. Since that time, many other reports have been made by the public media about institutional conditions and client abuse. These reports have kept deinstitutionalization on the agenda of citizens and legislators who would otherwise have little contact with services for handicapped people. More recently, Senator Lowell Wieker drew renewed attention to the deplorable conditions of many residential treatment programs for mentally disabled citizens (Wieker, 1985).

Research findings. Research has been another major source of influence on contemporary services for severely handicapped children and adults. Although it has been well established for over half of a century that handicapped people are generally able to function in community settings, if adequately supported (Lakin, Bruininks, & Sigford, 1981), the more recent examination of the effects of total institutions has provided the greatest research support to the deinstitutionalization movement. [illegible] beginning of the 1970s, a number of sociological and anthropological studies described the dehumanizing and debilitating effects of institutional placement (Blatt, 1970; Braginsky & Braginsky, 1975; Goffman, 1961; King, Raynes, & Tizard, 1971; Vail, 1967). The power of these presentations was supported by concurrent research suggesting that community-based placements presented clients with a substantially different reality (e.g., Edgerton, 1967; Jackson & Butler, 1963; Kraus, 1972; Krishef, 1959; Wolfson, 1956).

Research related to school placement has been much less dramatic than that of residential placement. Much of the support for the integration of handicapped young people into their neighborhood schools has been based on their right to participate in their own community, although some early studies questioned whether special education classrooms for mildly retarded students were any more effective than regular classrooms (Dunn, 1968;Johnson, 1962). More recent studies have demonstrated that integration of mildly handicapped students into regular classrooms with appropriate supports generally has been accompanied by greater academic and social student outcomes than those observed in more restrictive settings (Calberg & Kavale, 1980; Maddin & Slavin, 1983). The findings of research and current practices strongly support mainstreaming (i.e., the education of handicapped students to the maximum extent feasible with their nonhandicapped peers) as the treatment of choice for mildly handicapped children and youth. However, the extension of integrated education to severely handicapped students has come more slowly, not unlike deinstitutionalization, with people often withholding judgement pending outcomes on its effectiveness with mildly handicapped people. Importantly, recent research is beginning to provide evidence suggesting substantial benefits to severely handicapped people and their classmates in integrated programs (Brown, Branston, Jamre-Nietupski, Johnson et al., 1979; Liberty, 1985; Meyer & Kishi, 1985; Voeltz, 1980).

The results stimulated by many diverse social forces have been truly remarkable, not only in terms of the opportunities they have provided to handicapped people, but also in turn by what the results of those opportunities have taught other members of society about the potential of severely handicapped persons. These changes in our society were strongly influenced by a parallel set of philosophical concepts for organizing service programs.

Guiding Principles of Contemporary Services

Of all the terms that characterize the nature of recent changes in the philosophy and substance of contemporary services for handicapped people, none has been more influential than the term normalization. Normalization at its most fundamental level does not focus on services or imply an attempt to make disabled people normal; it merely sets a standard by which the treatment of people can be appraised. That standard is simply whether the residential, educational, employment, and social and recreational conditions of the individual are as close to the cultural norm for a person of that age as the extent of the individual's disability reasonably allows (Nirje, 1969; Wolfensberger, 1972).

There are two social policies that derive from the assumptions and values in the concept of normalization. One relates to the place of residence of handicapped people, termed **deinstitutionalization.** The policy of deinstitutionalization is concerned with reducing and preventing the need for residential living in large institutional environments. It is concerned with preventing admissions to institutional environments and promoting the placement, with appropriate habilitation and support services, of people in more normal living environments within the community. Deinstitutionalization became a dominant social policy over a decade ago and shows no signs of losing momentum. The belief continues to grow that this policy is sound and that the use of institutional settings for the provision of residential care for handicapped people still needs substantial reduction and alteration, if not eventual total elimination.

A second policy that derives directly from the perspective conveyed by the concept of normalization relates not only to residential care but also to educational, habilitative, work, and support programs in which handicapped people participate. This concept generally is referred to as placement in the **least restrictive environment,** although its underlying meaning might also be conveyed as "maximum feasible integration." The choice of least restrictive environment comes primarily from the ethical perspective that social agencies should assume the burden of proving probable benefit to a client before depriving a person of normal social conditions and experiences. In general, the policy of placing handicapped people in the least restrictive environment means that developmentally appropriate care, training, and support based on an individual's needs should be, to the maximum extent possible, provided in the types of community settings that are used by nonhandicapped persons. Inseparable from the concept of the least restrictive, appropriate placement is that: (a) needed services will be available, that is, persons needing educational, habilitative, residential, or other services will be provided them; and (b) there will be recourse (e.g., due process hearings) should there be disagreement about the appropriateness and/or restrictiveness of placements. These concepts, normalization and the least restrictive doctrine, first applied to educational and residential services, are increasingly being applied to the development of employment services for disabled citizens (Wehman et. al., 1985; Will, 1984).

The Changing Demography

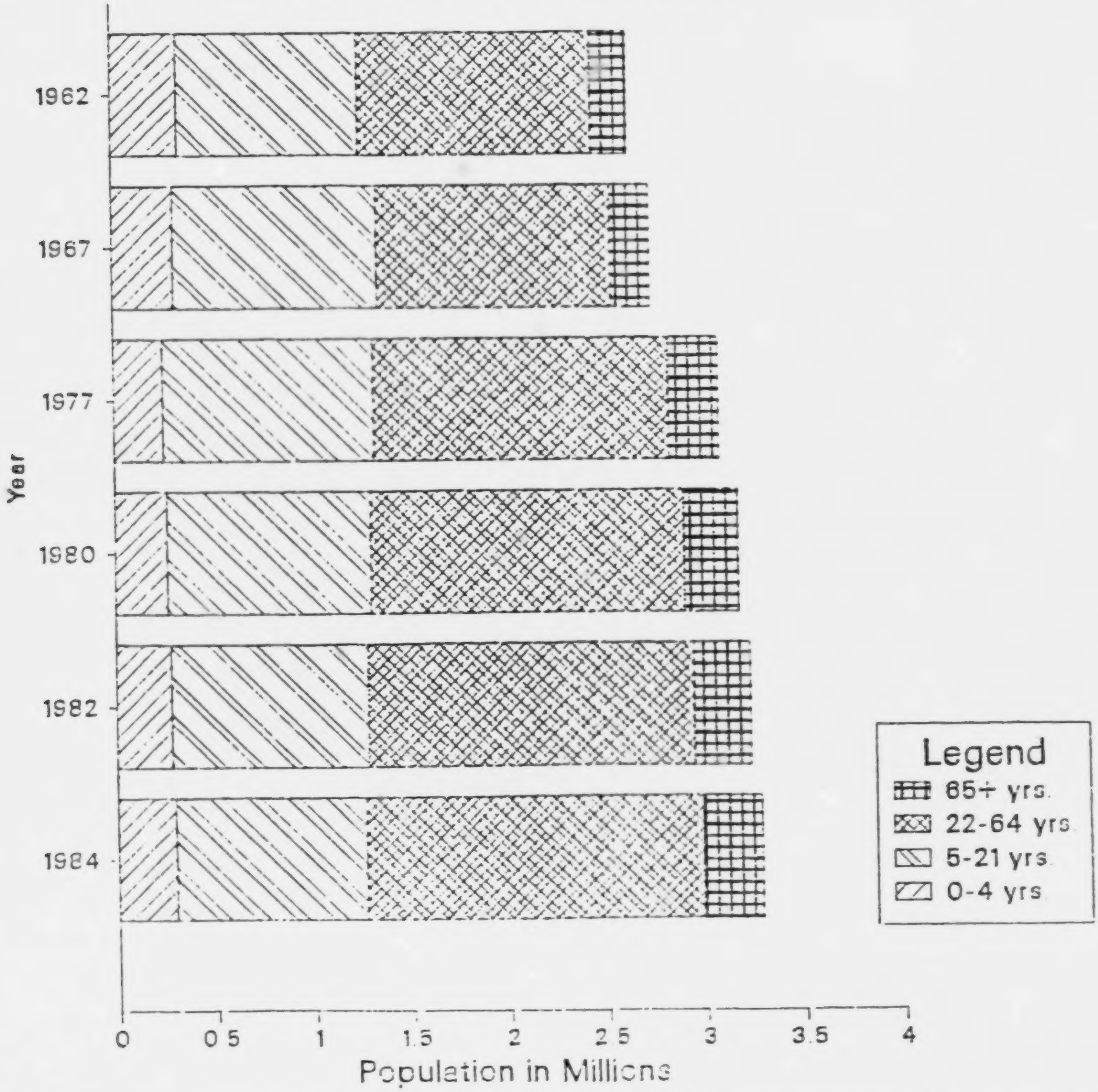
Another less obvious source of pressure for more accessible adult services is found in demographic changes in the U.S. population during the past 10 years. These dramatic changes are reflected in a higher average number of U.S. citizens, over preceding decades, in the adult years. Figures 1 and 2 present Census information on the numbers and proportions of U.S. citizens by year and age group. Today, approximately 62 percent of the U.S. population is in the age range above 22 years. Statistical data for disabled adults demonstrate parallel trends, accounting for much of the recent pressure to address the critical transition from special education to adult services and the expanded need for employment and adult services programs. Every indication from census statistics and other research reports is that these pressures will greatly intensify, in the years ahead, heightening the importance of addressing the adult service needs of disabled people with integrated and coordinated perspectives.

Trends Toward Integration and Decentralization: An Illustration

Implications for management deriving from the movement of handicapped persons into community oriented services is easily illustrated from historical information on residential service programs. From the funding of the first institution for mentally retarded persons in 1848, state institutions in the United States steadily grew in resident population through 1967. Fiscal year 1968 saw the first drop in history of the annual average daily population of public institutions for mentally retarded persons, a drop of about 600 persons from 194,650 to 194,000 (Lakin, 1979). A decade later, there were 148,752 mentally retarded persons in public institutions, a decrease of 23 percent in 10 years (Krantz, Bruininks, & Clumpner, 1979). Steady annual

Figure 1

Estimated Developmentally Disabled Population of United States in Millions

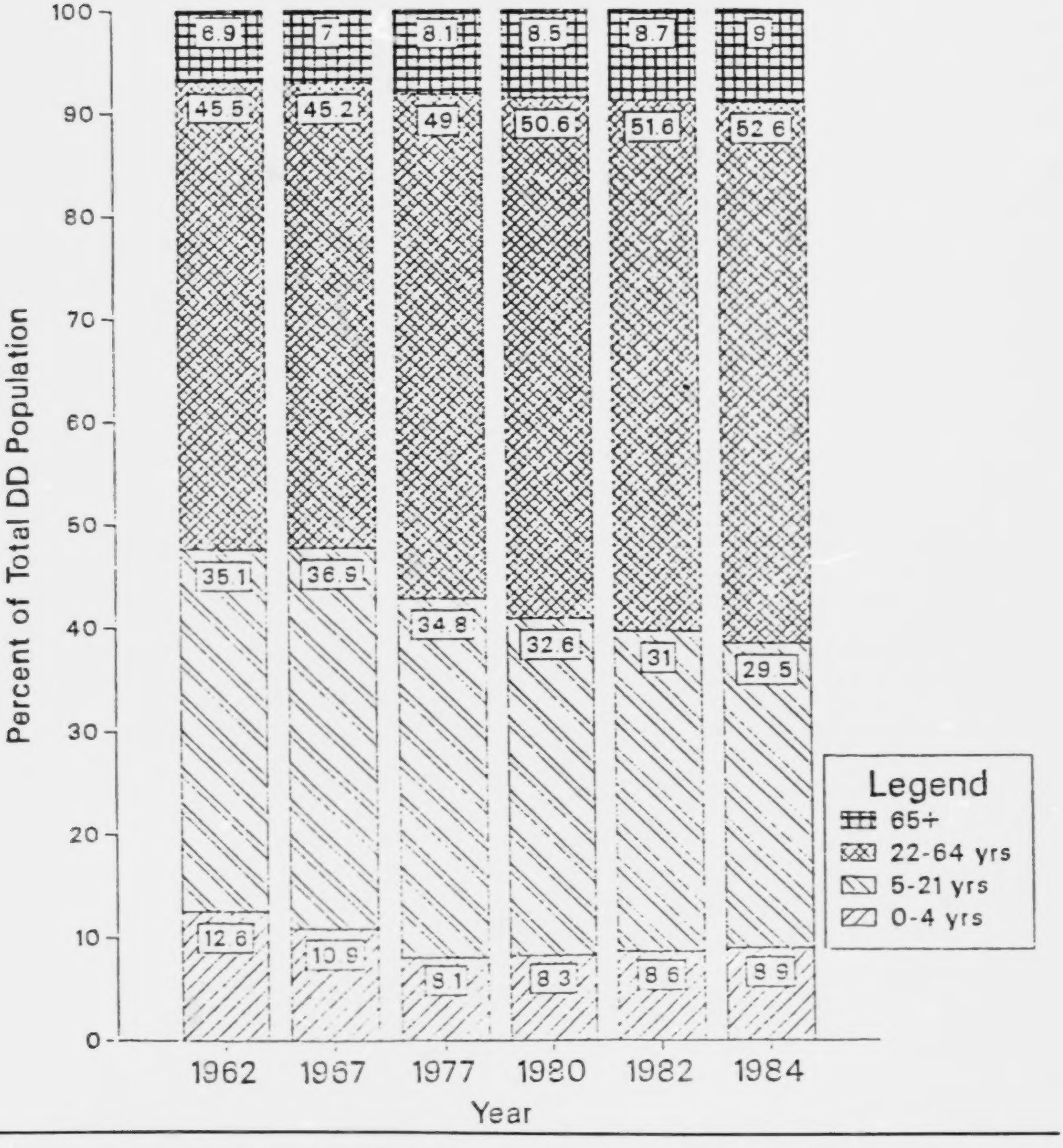


decrements in average populations have followed every year since, reaching a fiscal 1982 average of 117,160 (Lakin, 1979; Lakin, Bruininks, Clumpner, & Hill, 1982; Rotegard & Bruininks, 1983; Scheerenberger, 1982).

Matching this extensive decline in institutional placements was the rapid growth of community-based, private proprietary and nonprofit residential facilities. From 1969 to 1982, the number of residents living in privately managed, generally smaller community-based facilities quadrupled from 24,000 to approximately 98,000 (Lakin, Hill, & Bruininks, 1985). Paralleling this increase, the mean number of residents per private facility decreased from 47 (34 of whom were mentally retarded) in 1969 to 15 (12 of whom were mentally retarded) in 1982. Equally important, the focus of residential services changed from a few hundred facilities in the 1960s, mostly large public institutions, to well over 16,000 mostly privately operated

Figure 2

Estimated Percentage of Developmentally Disabled People by Age Category



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programs by the mid-1980s (Hill, Lakin, & Bruininks, 1984).

Many important characteristics of residential services changed during this 25 year period. One important dimension was the dramatic shift from public to private forms of management. This shift radically changed the role of state government agencies in residential services, substantially decreasing the need for direct centralized management and sharply increasing the need for indirect, decentralized management responsibilities (carried out largely through program approval, rate setting, quality assurance, and technical assistance rather than through direct administration). A second change resulted in a phenomenal decentralization of authority and responsibility. Rather than administering a few large programs that provided nearly all services in one location, states and local government units now had to organize highly diverse forms of services in many different agencies and locations. A third dimension was the changing role of government agencies from direct managers of programs and policies to mediators of many conflicting public forces involving legislators, parents, providers, employee groups and the legal system.

Despite such near revolutionary changes in views and practices, residential service and related service programs are organized today at the state and local government levels much as they were 10 to 20 years ago. Policies are carried out by a maze of largely independent and autonomous agencies. Community residential programs, for example, are most often administered by a different state office than the one that manages institutional programs. The placement of people from institutions into community settings is further impeded by the autonomy of local government social service agencies, whose financial responsibility is often increased by deinstitutionalization and social integration practices. To complete matters, services involving education, income maintenance, employment training, health and other services are all generally controlled by separate, autonomous agencies and boards.

The resources supporting integration and coordination of services for disabled citizens, unfortunately, are sparse and often ineffective. Recently, a statewide needs assessment survey conducted in Minnesota to assess barriers to the delivery of human services to severely handicapped people underlined this observation (Bruininks, Thurlow, Nelson, & Davis, 1984). Among the most significant problems cited was deficiency in client-based service integration strategies (i.e., case management). This finding has been supported by analyses of Wray and Wieck (1985), and by an earlier six state survey (Bruininks, Williams and Morreau, 1978).

Trends in residential programs are mirrored in other types of adult services. Similar trends toward decentralization of management are found in employment services, case management, leisure-recreation and other adult service programs. Halpern (1985) has argued correctly that the challenges inherent in the transition process between schools and adult services involve more than employment issues. Rather, the social integration and community adjustment of disabled citizens depends, as it does for all people, upon successfully addressing a number of their interacting and complimentary life needs.

The importance of taking an ecological and life cycle perspective regarding the needs of disabled children and adults was recently highlighted in a survey of 33 planners, providers, parents, advocates, and other professionals that was conducted to assess barriers to each of 11 desirable functions for community service programs (Bruininks, et. al., 1985). A structured, open-ended worksheet was used for gathering responses to four general types of questions: (1) What are the barriers that are impeding the implementation of the 11 desirable service functions? (2) What programs can be identified that avoid or reduce the impact of those barriers? (3) What policies have been or could be established, modified, or utilized to avoid or reduce the identified barriers? and (4) What should (or could) be the role of colleges and universities with respect to improving the general functioning of residential and related services for developmentally disabled people? A number of significant barriers emerged from this survey in several functional areas.

I. Barriers to an appropriate **range of residential options** include:
   A. Failure of the system to develop new cost-effective models based on individual needs;
   B. Definitional restrictions which deny needed services to people with developmental disabilities who are not considered retarded; and
   C. Lack of physical accessibility of residential sites.

II. Barriers to providing **habilitation activities** were:
   A. Lack of appropriate training activities and community environments for work placement; and
   B. Lack of appropriately trained staff.

III. **Social, leisure and recreation activities** offering opportunities for productive and enjoyable use of free time were considered to be limited by:
   A. Lack of recreational activities; and
   B. Staff who are not knowledgeable enough of environmental changes and training techniques to foster social skills.

IV. Necessary **resource allocation and financing** was impeded by:
   A. Budgeting, service reimbursement, and income maintenance policies that are institutionally oriented; and
   B. Eligibility criteria in federal income maintenance and health care programs that create disincentives to work.

V. Barriers to **individualized assessment, planning and placement procedures** included:

A. Poor match between the needs of persons and their living and other service environments; and

B. Assessment that is not reliable or valid for making appropriate decisions.

VI. Appropriate **support services** were often not provided to severely disabled people because of:

A. Inconsistent availability of support services in the community;

B. Lack of provider agency acceptance of a consumer oriented case management system;

C. Lack of clinical support services for persons with multiple disabilities;

D. Inconsistent availability and access to services which support family integrity and defray the care burden for families of developmentally disabled persons.

VII. Barriers to effective **information and evaluation** systems were:

A. Insufficient data for helping to determine types of service settings needed to match client needs; and

B. Data from the current system being used to advocate for new approaches rather than in client-based outcomes.

VIII. **Personnel management practices** that provide services needed by disabled people were impeded by:

A. Lack of effective recruitment and training for direct service staff; and

B. Lack of available qualified residential and other service personnel and a high rate of turnover.

IX. Barriers to the **promotion of social attitudes** that increase the acceptance and integration of developmentally disabled people included:

A. Lack of a systematic and ongoing program for building positive citizen attitudes toward persons with disabilities and toward service programs for this population;

B. Insufficient opportunities to get to know persons with disabilities in a positive, natural way; and

C. The pervasive beliefs among parents, service providers and the general public that many people are too disabled to live in community settings.

X. **Sharing knowledge and experience** was made difficult by:

A. Lag in use of existing technology for information exchange and training; and

B. Lack of available training and technical assistance to help programs address individual client problems; and

C. Lack of funds to support training, information and technical assistance or service personnel and parents.

XI. The major barrier mentioned by respondents to the recognition of **human rights and dignity** for developmentally disabled people was the lack of consumer involvement in policy making and operation of community services.

The results of this survey and many other recent studies (Conley, 1985; Halpern, Close, & Nelson, 1986; Schalock, Harper & Carver, 1981; Schalock, Harper, & Genung, 1981) serve to illustrate the many and varied consequences of inadequate concensus regarding purpose and strategy for providing state-of-the-art services for disabled people. Few of these many barriers to more effective services can be addressed through the initiative of a single agency or strategy. Starting some 20 years ago with a largely fragmented system for managing human services (Sanford, 1967), the force of public policy and practice since then has dramatically increased decentralization of services, the number of agencies in the service delivery system and the sharing of responsibility. Yet, these changes have not been matched by reforms in the structure and strategies for managing either public policies or service programs. All available analyses point to increasing fragmentation in purpose and strategy in human service programs for severely disabled adults, with a widening gap between prevailing practice and the need for more effective and coordinated approaches.

A Case for Change and Reform

It would appear from reviewing the evolution of services for severely handicapped youth and adults that "everything nailed down is coming loose." Such a pessimistic conclusion, however, is not entirely supported by available facts. That substantial progress has been made in achieving greater opportunity, services and social integration for severely handicapped citizens into our society is readily apparent in educational statistics contained in the Reports to Congress regarding Public Law 94-142 and other numerous studies and reports (Bruininks & Lakin, 1985; Lakin & Bruininks, 1985). It appears increasingly apparent, however, that such gains are losing ground to a host of factors, including budgetary constraints, increasingly strident conflict over purpose and strategy, newly emerging needs of adults with disabilities and approaches to public management more appropriate to an earlier era. For many diverse reasons, the service delivery system is undergoing at the local level considerable transformation. These changes require increased investment in experimental orientations toward policy development, planning and public management.

The Power of Values

The primary stimulus for change in service programs for severely disabled people these past two decades has been the pervasive influence of social values and philosophical precepts. These important social changes are captured by a variety of terms, such as **normalization, least restrictive environment, deinstitutionalization and mainstreaming.** The powerful influence of social thought and values on treatment of handicapped people can be easily observed in the history of the United States and Western Europe (Bruininks, Warfield, & Stealey, 1982; Kanner, 1964; Lakin, 1979; Scheerenberger, 1983). When social values reflected a more optimistic view of human potential, services programs in the 18th and early 19th centuries often emphasized social integration and normal lifestyles for handicapped people. As the impact of Mendelian genetics and Darwinian thought was applied to social institutions and public policy in the late 1800s and early 1900s, the public institutions of society emphasized strategies of social control and isolation toward handicapped citizens. This shift was driven by a pervasively held social philosophy and by values regarding the inheritance of deviance and the perceived need to control handicapped people, who were regarded as qualitatively different, through procedures of eugenics and institutionalization. The excessive and inappropriate use of IQ tests and the building of large, isolated institutions for mentally retarded and mentally ill citizens are two outward manifestations of negative social values upon the treatment of disabled citizens.

The influence of values and beliefs upon practice are no less influential today. At the risk of oversimplification, much of the fragmentation and marginal results (or at least unsubstantiated ones) for contemporary service programs can be traced to a lack of consensus on values to guide service programs and to the clearly misunderstood relationship between such precepts and current practice.

Much of the current philosophical foundation for services to handicapped citizens in the United States is traceable to Scandinavian influences. There is little doubt that Sweden, for example, provides services for handicapped citizens and their families that are quite congruent with the philosophy and practice of normalization. Forgetting for a moment that Sweden contains about 8 million people in a land mass the size of one of our mid-size states, its progress in creating community services is still a truly remarkable achievement. By a recent act of Parliament, for example, all institutions will be eliminated in just a few years (cf. Ericsson, 1985; Ericsson, Lerman, & Nilsson, 1985). (In Sweden today, there is only one large institution serving about 300 people.) The conclusion may be debatable, but it appears that the more rapid progress in community-based services for the severely handicapped in Sweden, compared to the United States is largely a function of widespread acceptance and implementation of social values among the government, citizens and providers that support community integration.

The first essential step in achieving greater reform, coordination of purpose and action, and effectiveness in service programs is through renewed and explicit articulation of clearly stated values and principles. This is not argument for developing a new list of values; rather it is a call for renewed discussion and greater consensus regarding the broader and more concrete meanings of normalization and least restrictive environment for approaches to employment, community living, training and social integration. With greater clarity and more widespread public acceptance, these ideals for practice can then be translated into benchmarks for planning and evaluating actions at all levels--federal, state and local.

It is being argued that much of current problems in human service programs are linked to lack of shared consensus on philosophy, principles and objectives, and secondarily to the strategies for managing public policies. The effective implementation of services at all levels requires first a coherent **policy framework** including clearly stated intent and values. Such values, to be effective, must then be translated into policy goals or broad standards. After articulation of standards, agencies at all policy levels can then formulate strategies and actions to achieve policy goals and measure the effectiveness of their service programs. The search for greater coordination and effectiveness in service programs begins, therefore, with a coherent policy framework comprised of clearly stated intent, goals and standards. Without consensus on the elements of a policy framework, there is little likelihood of achieving improved coordination of adult service programs.

One of the significant gaps in current practice is the translation of philosophical ideals (i.e., the **intent** of policy) into goals or standards to guide the implementation of policies. Changes in philosophy and practice have evolved, however, into increasing consensus on the importance of achieving appropriate standards for services at all levels of the service delivery system. It is essential to any effort at reform to translate the essential values of policy into a list of functions or objectives to guide the management of community service programs. A possible list of such functions and standards are listed below (Bruininks, et. al., 1985):

Direct Services

1. To provide basic maintenance (food, shelter, clothing) as necessary and a range of residential options that appropriately serves the varying needs of disabled people for different levels of care and different types of programs.

2. To provide habilitation activities that are focused on teaching disabled persons the skills they need to increase their level of independence, degree of social integration, and ability to fulfill valued social roles (e.g., work), and that promote the health, development, and psychological well-being of disabled people through appropriate, adequate, and timely intervention in response to their needs.

3. To provide social, leisure, and recreation activities that offer frequent and varied opportunities for productive and enjoyable uses of free time by disabled persons in integrated settings.

4. To establish resource allocation, budgeting, service reimbursement, and income-maintenance policies and practices that are clear, well publicized, and non-stigmatizing, that provide significant incentives for family and community living, and ensure continuity of noninstitutional alternatives.

5. To use individualized assessment, planning, and placement procedures that gather and utilize information to determine the nature and quantity of services needed.

6. To provide individual case managers or program coordinators to suitably link the individual disabled person with providers who will deliver appropriate services in the least restrictive, most normalized, appropriate placement.

Indirect Services

1. To maintain information and evaluation systems that gather, aggregate and utilize data on individual clients, programs, and systems to establish objectives for services and policies, assess the effectiveness of services and policies in meeting goals, and to modify services and policies as indicated by evaluation results.

2. To establish personnel management practices that recruit, train, utilize, and retain adequate numbers of skilled professionals and paraprofessionals to provide the services needed by disabled people.

3. To promote social attitudes, professional commitments, community experiences, and citizen expectations for public laws, regulations, and policies that increase the acceptance and integration of disabled people.

4. To develop and share knowledge and experience among service providers, academic and research institutions, government and private administrative agencies, advocacy/consumer organizations, and natural and surrogate family members about available services, effective practices, new technologies, special opportunities, and useful policies in local, state, and national spheres.

5. To promote the recognition of human rights and dignity for disabled people, including maximizing the opportunities for consumer involvement, personal choice and self-advocacy.

Achieving greater coordination of services must begin with an explicit and logical coherent policy framework, both within and across different legislative mandates, regulations and guidelines. The policy framework must include a clear statement of intent through values that reflect state-of-the-art concepts, clearly articulated goals and standards of performance. In considering issues of coordination among service programs, attention is too often and prematurely placed upon fixing responsibility for lack of performance on a single agency, or moving toward establishing general interagency agreements. But, the search for improved coordination and integration of services for citizens with disabilities begins and ends with values and standards. Organizational strategies to achieve more coordinated services, while important in their own right, represent means to ends and only become meaningful in the context of values that promote the full potential and meaningful social integration of disabled citizens.

The Importance of Information

Persons with severe disabilities require services from multiple agencies. Effective coordination of such services, however, depends in large measure upon availability of accurate information on the characteristics and needs of disabled people. Assembling reliable and valid information is perhaps most critical in organizing services for severely disabled clients who present complex needs that must be addressed by more than a single agency. Unfortunately, communication across agencies is invariably awkward and inefficient in the planning of services due to a pervasive deficiency in accurate and timely information.

The Amendments to the Education of All Handicapped Children Act (Public Law 98-199) implicitly recognize the essential importance of information in planning for the transition of handicapped youth from school to adult services. The Amendments require that local and state education agencies report, as part of the annual child count, the anticipated service needs of youth by handicapping conditions who are leaving school. From an interagency perspective, another important requirement is that this information must be used by state rehabilitation agencies and developmental disabilities councils in their plans submitted to the federal government.

While Public Law 98-199 does not prescribe a specific procedure for collecting such information, it is likely that school districts will develop such information by employing some form of planning conference involving parents and adult service providers. A number of states are already experimenting with transition or dismissal conferences. It is also likely that personnel of school districts and adult service agencies will increasingly use common assessments of clients and procedures to facilitate communication and the sharing of information among agencies.

The problem of developing common information across agencies is being addressed currently in several projects to implement a standardized client-based management information system in Minnesota and Utah, using the **Inventory for Client and Agency Planning** (Bruininks, Hill, Woodcock, & Weatherman, 1986). The **Inventory for Client and Agency Planning** (ICAP) provides extensive information on client status, development and service needs by using standardized items to report demographic information, diagnostic status, functional limitations (e.g., vision, hearing, mobility, health), development of adaptive behaviors and current service usage and service needs. The structure and content of the ICAP is designed to facilitate planning of services across agencies. By employing such standardized assessments, school, parents and adult agency personnel share common information. The sharing of information is a necessary foundation for improving communication and coordination of effort across agencies.

The new anticipated services reporting requirement under Public Law 98-199 offers a unique opportunity to increase communication between schools and adult service agencies on the post-school needs of disabled youth. It forces an assessment of longer range service needs of disabled youth and the sharing of important information across agencies. Hopefully, the perceptive intent of this legislation will be matched by advances in the development of common information and shared processes for planning services that involve family members (and the disabled person whenever possible) and the various agencies that must address the complex needs of disabled youth and adults.

The Value of Strategy

The diverse needs of severely handicapped adults and their families for assistance can seldom be found in a single agency or location. These service needs are detailed in the Developmental Disabilities Act of 1984 (Public Law 98-527), the Educational for All Handicapped Children Act, the Rehabilitation Act and in numerous studies and reports. Achieving greater integration of such diverse services across many largely autonomous agencies and levels of government today has largely been left to the devices of families and individual service providers. Lack of coordination among services is invariably cited as a significant barrier by parents and service providers to the development and integration of severely handicapped adults (Calkins, et. al., 1985).

Lack of coordination of services for handicapped individuals is a problem within and among all service agencies. Many studies, for example, report dissatisfaction and limited involvement among parents in working with schools as part of the individual educational plan process (Gilliam & Coleman, 1981; Goldstein & Turnbull, 1982; Lynch & Stein, 1982). Halpern (1985) further reports from an extensive survey of parents and teachers in Oregon very limited coordination of services on behalf of secondary age handicapped students between special education and vocational education administrative units within school districts. These documented illustrations of inadequate coordination of services involving special education programs are not intended to unfairly indict the schools. Similar examples of such problems could be cited regarding all other service programs and agencies for needy people. In reports by the General Accounting Office (1975, 1977), for example, over 30 federal programs were found to provide services to handicapped children; and over 135 agencies and programs had some responsibility for deinstitutionalization of mentally disabled people. This situation at the federal level has changed little in the past 10 years and is also mirrored at the state and local levels. The need for collaborative efforts in education and human services is both obvious and urgent, particularly in future years when service dollars are likely to lag behind human needs and inflationary changes.

The primary means of addressing current problems of service coordination is through legislative and regulatory requirements to develop individual service plans at a client level and interagency agreements among federal, state and local agencies. By 1979, state education agencies had negotiated over 150 formal interagency agreements (Bureau of Education for the Handicapped, 1979; Hockenberry, 1979). Over 35 states now have such agreements regarding transition services alone between special education and various adult service agencies (Wehman et. al., 1985). These strategies are undoubtedly useful, but they are not sufficient to improve efficiency and coordination of services. It is not known whether these documents contain explicit objectives written in a form that expresses tangible, expected results or whether they ostensibly designate and describe lead agency status and functions for specific services or service coordination. From a limited analysis of several existing agreements, the general approach seems more oriented toward documenting existing legal mandates and responsibilities, still leaving considerable ambiguity regarding key responsibilities for achieving more precise service outcomes. The persistent findings and observations in various surveys regarding deficiencies in case management services illustrate the inadequate results of existing service planning and cooperative planning approaches (Bruininks, et. al., 1985; Calkins, et. al., 1985).

Extensive literature and ideas in the area of interagency collaboration are found in a number of technical studies on service integration projects in human services (Demone, 1978; Gans & Horton, 1975; Joint Center for Human Services Development, 1976). Success in previous demonstration efforts usually involved (1) approaches that addressed the personal needs and feelings of individuals, (2) training to clarify roles and reduce conflict, (3) use of outside agencies or consultants, (4) employment of structured organizational development strategies (e.g., team building, conflict management), (5) full analysis of important organizational and community contextual factors (e.g., systems analysis procedures) and (6) strong leadership. The Joint Center for Human Services Development (1976) study concluded that:

> ***Given the present state of integrated services, efforts are not likely to succeed without the use of training, technical assistance and other development strategies. The integration of services is an interactional process, not a program or a product or a place (p. 10).***

The issue of coordination among services is broader than a problem of seeking more effective management across agencies and programs through interagency agreements. The path to more effective reform of our educational and human service agencies cannot be traversed merely by adopting conventional strategies such as interagency agreements or by the creation of greater compartmentalization of service programs. Weiner (1978) has argued instead that facilitating coordination of services among previously autonomous units (often called networking) requires application of four clusters of applied theories and organizational techniques: (1) integrating mechanisms, (2) participative management, (3) generalist management, and (4) networking.

Progress toward better coordination of services will be enhanced if the issue is viewed from an interorganizational and ecological perspective. It is widely accepted that the behavior of individuals is influenced greatly by aspects of their environments. This commonly accepted principle of human behavior is no less true when applied to the actions of organizations. The behavior of organizations is thus substantially affected by influences of a broader society (Myrtle, 1983; Zeit, 1975). This perspective is summarized by Zeit (1975):

> ***Organizations interact with other organizations, but this interaction is conditioned by the power of groups who control or who are affected by organizations, and by established political, legal and administrative structures. Individuals or groups which may 'control' organizations do not do so voluntarily. They are themselves acting as a result of their positions as individuals or groups in a societal system (p. 46).***

It is essential that efforts to achieve greater coordination of services consider the many environmental factors that influence the adoption of policies and the ongoing operation of agencies. Viewing the full environmental context of a problem, and the interorganizational behavior of agencies, is a necessary prerequisite to the achievement of concrete results through the use of formal planning and management strategies.

The many problems in implementing public policy have been the subject of frequent analysis and research in the past several years (Bardach, 1977; Edwards, 1980; Hargrove, 1975; Pressman & Wildavsky, 1973; Robertson, 1984). Most studies of the policy implementation process have generally documented disappointing results when compared to initial legislative intent. Such results in the field of disability have been subjected to far less research compared to areas of employment and mental health policy, but a number of analyses point up a variety of significant barriers to effective implementation of public programs (Conley, 1985; Lakin, Hill, & Bruininks, 1985).

Solutions to problems inherent in implementing effectively coordinated service programs are admittedly varied. Many problems can be solved only through legal changes or judicial fiat. Others, however, are amenable to improvement with the aid of sound planning and management procedures. Planning models based upon systems theory provide considerable potential for addressing the implementation of public policies and the service coordination needs of severely handicapped adults. A system is generally defined as an entity, physical or conceptual, consisting of related parts (Catanese & Steiss, 1970; Ackoff, 1974). Systems models and planning methodologies are frequently used to analyze and design solutions to complex problems.

A variety of systems planning tools can be easily applied to nearly every stage in the policy implementation and management process. Very useful and well organized procedures, based upon systems theory and planning concepts, are found in Schalock (1983) and Delp, Thesen, Motiwalla, and Seshadri (1977). The **system definition matrix** approach, for example, provides an organized means of defining factors and relationships among factors of a problem, an organization, or a service delivery system. Using a matrix with defined dimensions and functions (see Figure 3) allows a careful analysis of critical functions and relationships in a service delivery system. Such analyses are a necessary first step in defining specific strategies to address service coordination problems. Another of many available and useful strategies is **force-field analysis** developed by Kurt Lewin (Fordyche & Weil, 1971). This procedure is particularly useful for identifying barriers to the solution of a problem and the opposing forces to such barriers (resources) that can be exploited to solve it. The purpose here is not to recommend or thoroughly describe any of the many available strategic planning and management tools to address problems of coordination in implementing policy. Rather, it is to suggest that the use of such tools can be extremely useful in considering the necessary factors for achieving more effective coordination of services.

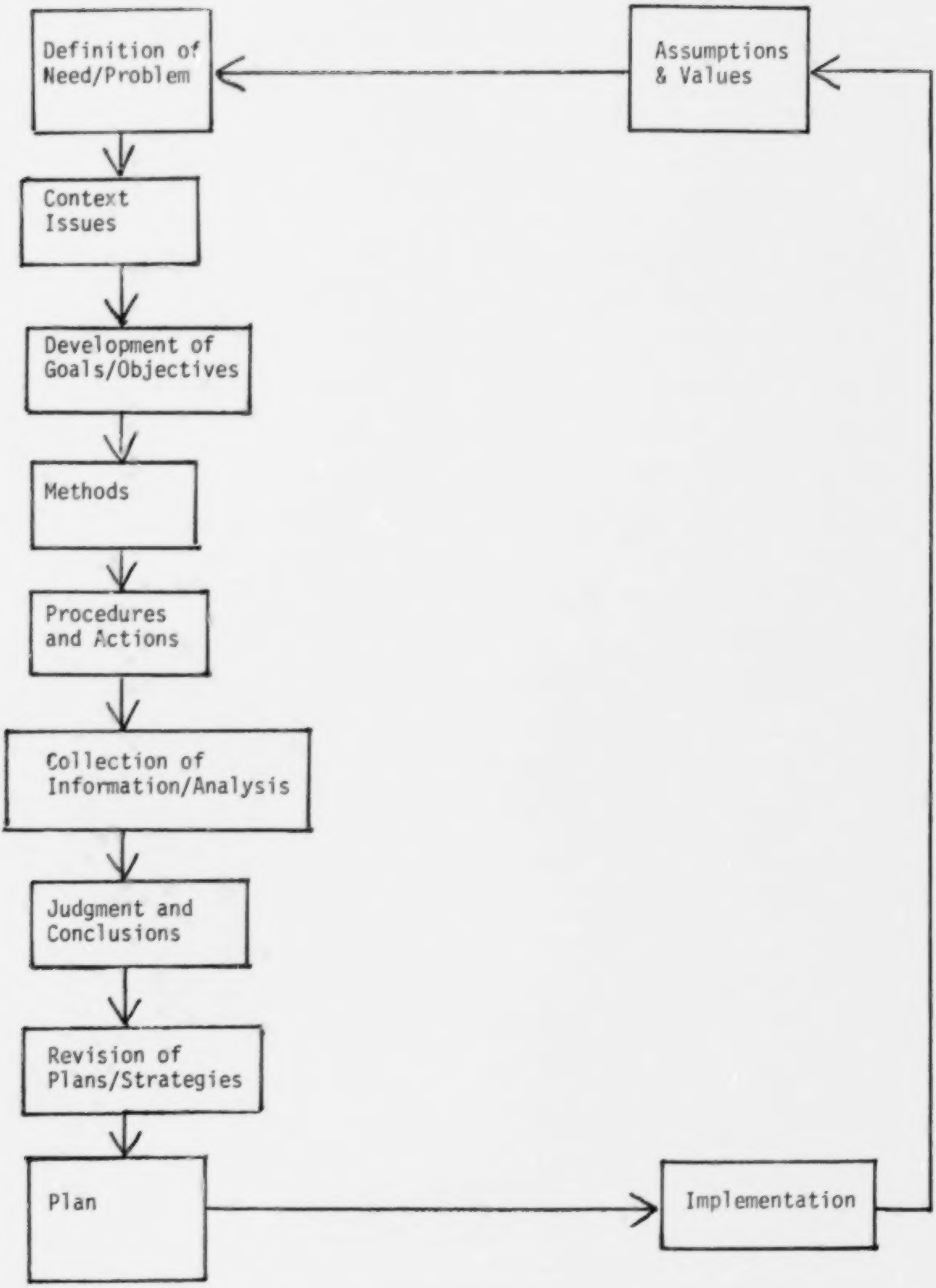
Figure 4 presents a systems diagram for planning and managing service programs. Importantly, the model is guided initially by assumptions and values and relies upon careful analysis and evaluation of results. It further assumes that effective planning considers the total environment of a problem, including interorganizational relationships involving programs and the broader community, and that its solution is guided by value considerations, a plan of action with objectives and strategies, and a means for evaluating results and modifying, as needed, the behavior of an organization. Many such models exist in the planning and management literature. What is necessary for reducing fragmentation and increasing coordination of services is a view that comprehends the personal and organizational relationships inherent in a problem, a set of tools for attacking its solution (usually in interaction with parents and key actors in the service delivery system), explicit descriptions of decisions and a commitment to evaluate decisions by results. Despite our multi-billion dollar service delivery system, few managers in key positions have been

Figure 3
System Definition Matrix Format: A Hospital System

	DIMENSIONS				
	FUNDAMENTAL	**RATE**	**CONTROL**	**INTERFACE**	**STATE**
PURPOSE	Treat patients		Malpractice suits filed		Provide preventive care
INPUT	Ill and injured people	50 cases/day	Schedule surgery referrals	Emergency medical service	
OUTPUT	Patients released	40 releases/week	Hospital review board	Outpatient referrals morgue	
SEQUENCE	See flowchart*	Average stay: 2 days	Monthly bed check (random)		
ENVIRONMENT	Location humidity, temperature Supportive climate		Automatic control, Staff T-group		
PHYSICAL CATALYSTS	Structure: beds, equipment, supplies	Depreciate on 10 year cycle, weekly purchase	Audit quarterly		Double capacity in 10 years
HUMAN AGENTS	Medical staff, secretarial staff, custodial staff		Hospital review board	Medical school system	
INFORMATION CATALYSTS	Staff assignments, patient care, charts planned, referrals			County public health office	Computerized patient care system

PLANNING AND MANAGEMENT MODEL

Figure 4


Definition of Need/Problem
Assumptions & Values
Context Issues
Development of Goals/Objectives
Methods
Procedures and Actions
Collection of Information/Analysis
Judgment and Conclusions
Revision of Plans/Strategies
Plan
Implementation

systematically trained in currently available strategic planning management methods.

Our central premise is that effective coordination of services for adults with disabilities cannot be achieved merely through recourse to more centrally employed strategies in involving administrative reorganization, development of new agencies, or interagency agreements. Such strategies, while possibly useful, often underestimate the drive of organizations toward autonomy and specialization, and the many conflicting environmental factors that affect the implementation of public policy (Bardach, 1977; Hage, 1975; Zeit, 1975). There are, nonetheless, some promising strategies for addressing problems of service coordination. Over the past several years many strategies have evolved in the field of high technology to address the solution of technical development problems. These strategies involve forming ad hoc organizations or coalitions of resources (funds, personnel, etc.) from a variety of areas within and across organizations to solve major problems. The key to such approaches is the perception of problems (e.g., the lack of service coordination) as a project requiring the joint resources of several divisions, agencies and even individuals for its solution. Once the problem is clearly defined, resources and actions to solve it are described in a project management plan (Kerzner, 1979). The solution of the problem is to be addressed through joint actions. This approach takes a somewhat different view than more conventional perspectives on organizations. Most human service organizations are structured to carry out different functions such as intake, budgeting, and accounting within a limited mandate. They respond inflexibly to challenges outside their perceived areas of responsibility. An alternative conception of organizational resources might involve viewing the problems of service coordination from a **matrix management** perspective. (Galbraith, 1971;

Lawrence, Kolodny & Davis, 1977). Under this more ad hoc model of management, the problem of service coordination in the transition from school to adult services could be viewed as a project of multiple agencies. Each agency under a project management plan would provide resources needed from its various functional divisions to handle transition or service coordination problems. The key features of this model are (1) the development of a clear plan with objectives stated in terms of measurable results, and strategies for achieving them (see Figure 4); (2) a management structure of shared resources and defined responsibilities to address the problems, (matrix concept), and (3) a plan for monitoring and assessing its effectiveness. Thus, personnel in educational and rehabilitation agencies should combine resources to address service coordination problems according to a plan that assigns their time jointly from normal agency responsibilities to the "new" service coordination project.

Hage (1975) has argued for the formal establishment of joint programs or coalitions to address multiple needs of severely disabled people. After careful study of several mental retardation service integration projects in the 1960s, he concluded that coalition programs were needed with joint funding to address multiple problems requiring lateral and longitudinal treatments. He further recommended the formation of supracorporate boards to oversee such efforts, comprised in equal proportions of community leaders, professionals and consumers. This model of joint organization or coalitions could be combined with systems planning perspectives described earlier in which specialized resources of agencies could be organized as projects to address the solutions of major service coordination problems.

The transition between school and adult service programs for individuals with severe disabilities admittedly requires the joint action of many agencies and people. Concepts discussed in this section could be applied to service coordination problems in a variety of ways. Many people have argued for developing a joint individual transition services plan for disabled youth at least two years before they leave special education services. (Halpern, 1985; Weatherman, Stevens & Krantz, 1985; Wehman et. al., 1985). Using project and matrix management concepts, such a plan would be developed jointly with the aid of family members, the disabled individual, school personnel and various adult services providers. A special ad hoc coalition could be developed, with perhaps initial coordination responsibility given to local education agencies, with specially designated personnel and other resources of each agency contributing to the effort on an agreed upon formula basis. These resources could be committed through budgetary reallocation and/or through the infusion of new funding from each of the participating agencies. The plan would identify objectives, needed resources and lead agency responsibility for services during the secondary education, transition and post-school periods. Importantly, using a project model would make participation and commitment to this process a mandated service required of all participating agencies, with fixed budgetary and programmatic contributions for the joint responsibility of devising the service plan. It would also require the development of results oriented action agreements that define procedures for formulating plans and carrying out responsibilities. For this concept to work effectively, changes consistent in support of the service planning effort would be needed to be made in the policies of all participating agencies (i.e., the development of a consistent **policy framework**). Its successful operation, however, would likely depend substantially on the application of strategic planning methodologies involved in managing complex projects.

Approaches used to confront the issues of fragmentation and inadequate coordination of services usually vary along a continuum from centralization of authority, through administrative reorganization, to decentralized approaches reflected in the development of interagency agreements. Neither strategy has proven particularly effective in solving problems for people who present multiple problems and who need multiple resources. The intensive, centralized approach is only slightly less politically popular and feasible than strategies to make radical revisions in state and federal tax codes. (It is difficult to recall many, or perhaps any, politically popular leaders whose reputations depended upon successful administrative reorganization of government agencies.) Besides difficult political obstacles, more substantial administrative reorganizations often ignore the considerble value and need for specialization, the special expertise of most organizations and the considerable drive to maintain their organizational autonomy. On the other end of the continuum is the oft used and misused interagency agreement method of increasing service coordination. Without the benefit of strategic planning methods and outcome oriented objectives, however, such more informal strategies often do little more than document existing jurisdictions and practices. At this stage in development of services for severely disabled adults, a variety of approaches that employ more systems oriented perspectives, ad hoc organizational strategies, and results oriented management strategies seem necessary to increase the appropriateness, availability, coordination and effectiveness of service programs.

The Value of Orientation in Action

Fragmentation in human service programs can be addressed through a number of actions and strategies. **The One Minute Manager** (Blanchard & Johnson, 1981), a best selling book for many months, was a popularized description of how principles of behavior first proposed by B.F. Skinner (1938, 1953) could be applied to interactions involving supervisors and employees. Thompson and Wray (1985) have argued persuasively that Skinner's **three-term contingency model** can be applied to the improvement and coordination of services at six different organizational levels: the client, the family, the community, local government, state government and the federal government. This model includes: (1) "setting environmental circumstances, (2) actions, and (3) consequences of actions" (p. 279). They illustrate how behaviorally oriented analysis and application of behavior principles can be applied at these six organizational levels to achieve more responsive service programs, using a seven step process: (1) analyze the problem, (2) perform a functional analysis of problem-related behaviors, (3) designate target behaviors or outcomes, (4) formulate behavioral objectives, (5) develop an intervention strategy, (6) implement the intervention strategy, and (7) evaluate implementation of desired actions. The importance of this strategy lies in its well described approach, the specificity of objectives stated in terms of service outcomes, the careful arrangement of environmental circumstances to support objectives and the measurement of results. This strategy represents a more promising approach for increasing the coordination of services to severely handicapped adults, with considerably less investment than ones requiring major legislative or organizational reform.

Other strategies may be equally promising in facilitating organizational reform of human service programs. An often overlooked tool is the potential power of federal discretionary research and development funding to create and implement innovative practices. Experimental demonstration efforts, however, frequently have little impact upon current practices in educational and other service programs. There are many reasons for the failure of demonstrations to more pervasively influence model practices. One chief problem is that managers, in the words of Campbell (1969), get trapped by their own rhetoric and politics. Having persuaded legislative bodies regarding the utility and effectiveness of service programs, managers all too often fear to subject them to critical evaluation. While the politics of this perspective is admittedly safe, in the short run, they unfortunately create a climate which is conservative and antithetical to innovation.

What is needed to address current service delivery problems is the development of more planned experiments that are designed to be consistent with accepted values (see earlier discussion) and acceptable experimental research procedures. Too few responses to requests for proposals meet either the values test or the minimal requirements of experimental procedures. The research issues in conducting necessary experiments in service programs are discussed thoroughly, with suggested solutions, by a number of authors (Butterfield, 1982; Cronbach, 1980; Heal, 1985). Vast improvements could be realized in current federal and state investments if demonstration projects required tangible interagency collaboration based upon explicitly stated objectives and measurement of concrete outcomes, including the involvement of third party agencies such as universities to assist in developing adequate research and evaluation designs. Failure to adhere to such simple concepts too often yields little change either in individual or in organizational behavior, or produces results that cannot be assessed, disseminated or replicated. James Bryant Conant (1953), in **Modern Science and Modern Man,** argued that one of the primary values of science is to reduce the level of empiricism or trial-and-error in everyday life. Without an experimental orientation in which practices are tested, and evaluated, it is doubtful that much progress can be made to improve the quality and coordination of service programs for severely handicapped citizens.

Careful research and evaluation of practice is only an initial step toward improving practice. Today one of the great weaknesses in service programs is the absence of timely and understandable information. It is indeed ironic, in an information age in which the volume of knowledge doubles every few years, that so little integration of information is available at the level in which services are provided. The United States leads the world in applied research on the needs of severely handicapped people even though only a small fraction of one percent of the funds appropriated for services is spent on research and development activities (Braddock, 1985). Unfortunately, only a small fraction of even our current paltry investment in research and development is spent on synthesizing and disseminating information to improve practice.

The argument has been advanced that coordination of services for severely handicapped adults can be enhanced through application of behavior theory, experimentally based research and demonstration programs, and more effective transfer of information. These strategies would still likely achieve little, however, without the commitment of government agencies at all levels. Presently, the need for cooperation and coordination of effort possesses too little value. The incentive to compete among agencies and individuals clearly outweighs that supporting coordination of effort. What is needed is a strong commitment at all levels of government to the notion that the service needs of severely handicapped citizens can be addressed only through cooperative goals and strategies. To illustrate this rather obvious point, federal departments could require that applications for discretionary funding to address complex service needs of disabled people seriously attempt to solve important service coordination problems. A community oriented job training and placement program, for example, might involve specific contributions from health, education, rehabilitation and other agencies, all of which would be carefully delineated in terms of concrete objectives, actions and measurement of project outcomes. In short, the need for collaborative action would be given value, thereby creating a climate supportive of efforts that stress achievement results over process.

Suggested Actions Toward More Accountable Services

The issue of coordination is just one aspect of needed reform in services needed by people with disabilities. Approximately three years ago, a group of 25 knowledgeable parents, researchers, government managers and service providers was convened to address substantive policy, research and management issues in services for severely handicapped people (Bruininks & Putnam, 1984). The group represented a variety of responsibilities and disciplines, including the fields of special education, law, management, social work, mental health, health psychology and economics. During two days, a modified Nominal Group procedure (Delbecq, Vande Ven, & Gustafson, 1975) was used to generate ideas related to several issues; including: (1) the contemporary condition of services; (2) the likely future directions for these services; and (3) recommendations for policy and practice that would further promote the opportunity for handicapped people to live and learn in the least restrictive environment. Conference participants were asked to consider the following questions: (1) What is known? (2) What information is needed? (3) What actions and strategies should be advanced to improve research and practice? Three specific areas of focus addressed by the group were **governmental policy** (laws, regulations, funding strategies), **management of services** (integration, quality assurance and cost effectiveness priorities), and **interventions** directed at handicapped children and youth and their family members. The conference conclusions and recommendations are reported in Tables 1 to 4.

Table 1
Conclusions and Recommendations on Status and Trends

There will be increasing development and application of technological innovations in services to handicapped persons.

More emphasis will be placed on the client/environmental match.

Comprehensive financial incentives will be commensurate with programs that are compatible with policy objectives regarding normalization and least restrictive environment.

Interagency coalitions of the 1970s will crumble due to competition over scarce resources and ideological schisms.

Funding will require documentation of client gains, employee productivity, and decreased public liability.

There will be a reluctance of state and federal government to regulate quality of programs coupled with a weak state-of-the-art in determining program quality.

There will be instability in programming and funds for community based programs due to economic recession.

Outcome studies will occur on types of state systems and interventions (e.g., legal, administrative reform, advocacy and training).

There will be problems in moving from judicial remedy to legislative mandates for services.

There will be a wholesale transition from debilitating institutional settings to least restrictive environments.

Institutionalization will be prevented through early support systems from birth.

Access to all available community services will be effected through provision of incentives for families, handicapped people and service agencies.

There will be an increase in the use of "ecological inventories" to identify "normal" behaviors across all dimensions of development and performance.

Improved techniques will be developed to assess personal preferences of handicapped individuals for assistance and services.

Table 2
Recommendations for Research and Development Priorities

Congress should phase out federal funding for institutions and reallocate these funds to community services.

There should be more effective research, dissemination, and policy advocacy directed to legislative bodies.

Research and Development funds under 94-142 and 95-602 should be allocated to promote increased direct care level employee retention and productivity, through assessment of quality and quantity of staff time and client growth.

Three model sites should be established to develop decision models for services based on client outcomes, with funding related to those outcomes.

Research and development programs should be supported at state and local levels to develop reimbursement strategies that eliminate regulatory mandates prohibiting the pooling of funds and other barriers to deinstitutionalization.

Discretionary resources should be allocated for evaluating "best practices" and the translating of research into practice. Priority areas for such work should include: case management, funding incentives, reimbursement methods, client development, and program monitoring systems.

Assessment should be done of effects of due process and advocacy monitoring (use of parent and clients) versus traditional quality monitoring of services.

Evaluations should be conducted of public/private collaboration through performance contracts and of public ownership of residential facilities with private management.

Develop measures for assessing client outcomes and appropriate measures to assess success of handicapped people.

Develop and research incentives for collaboration between day and residential programs that are based on stated goals and expected outcomes for handicapped people.

Develop and research management information systems (including data on services, costs, and outcomes) to describe and monitor client progress and service programs.

Promote ecologically valid and experimentally controlled evaluation and outcome research on services for handicapped people.

Conduct national experimental studies and survey judgements of critical populations (e.g., parents, clientele, staff) on services to handicapped persons.

Focus more on the implementation of strategies and public policies, including behavior analysis of service systems (see chapter by Thompson and Wray, this volume).

Develop and research interagency services which serve clients across the life span within natural environments.

Conduct research, development and consultation services to assist parents in lifelong planning for their handicapped children.

Table 3
Conclusions and Recommendations for Improving Policies and Practices

Develop a voucher and contract for services system in which money follows the client rather than direct reimbursement of service programs.

Apply behavior analysis evaluation and management techniques to understand and promote the effects of change in human services.

Focus on process and outcome criteria in accreditation and certification standards.

Conduct assessment and training of handicapped people in natural environments, focusing on functional skills.

The President and Congress should reaffirm their commitment and allocate financial resources to the implementation of Public Law 94-142, Public Law 95-602, and Section 504.

Minimize disincentives and encourage community integration through incentives at all levels, such as government support for families.

Designate lead agency status, chronologically by age of child to follow clients (for example, prenatal-perinatal = Health, preschool-age 21 = Education, age 21+ = Habilitation Services). If there are multiple service needs, then coordination of habilitation services would be assigned to the lead agency.

Identify a range of service functions for clients that includes costs and pooling of resources.

Federal regulatory policies on financing should be modified to permit experimentation with combining resources at the local level (both education and human services).

Break down the continuum funding system and open it up to innovation (e.g., fund individual service plans with the case manager as the fiscal program agent) and permit performance contracting.

Allocate resources for integrative programs and practices (to be consistent with recommendations of The Association for the Severely Handicapped).

Incorporate reliable multivariate measures of effectiveness that focus upon client gains and development.

Develop and implement models for cost-benefit analyses to assess the effects of services.

Develop procedures and determine needed content for distributing information on state-of-the-art practices across components of the service delivery system.

Table 4
Other Issues and Recommendations

Use federal tax incentives to generate private capital for small scale living arrangements and adult day programs (capital funding).

Have Congress clarify "intent" of the Title XIX Omnibus waiver.

Compare a generic case management system (elderly, MI, MR, CD) in a rural context with present system.

State program offices should be responsible for disseminating state-of-the-art practices so as to provide competent quality assurance plus technical assistance services.

Fund a state legal advocacy office and one mental health advocacy clinic in a law school in each state.

When implementing cutback strategies, provide maintenance of some funding for prevention. (If only the most severely handicapped received programming, prevention programs would suffer.)

Disseminate and promote more parent monitoring as a grassroots, nontraditional quality assurance mechanism.

Research service strategies for non-majority and rural populations.

Provide training in how to manage financial cutbacks and improve productivity in service programs.

Conduct research on elements that contribute to innovation in service programs (e.g., through organizational case studies).

Set research contract requirements based upon client and service process/outcome measures.

Develop effective client-based management information systems for planning, monitoring and improving service programs.

Research and employ marketing strategies (including use of existing center networks, public information systems, and public relations specialists) to disseminate information on successful assessment, intervention and service practices.

Develop techniques of selective dissemination of current information (e.g., using electronic mail options via micro computers) with a focus on consumers.

First, there was overall agreement regarding the need for a behaviorally oriented approach to funding and evaluation of programs based on client needs and evidence of client progress. It was felt that providers of educational and social services should be made more accountable for individual client outcomes. To accomplish this task, it was recommended that sound measures be developed for assessing outcomes and determining "success" of programs, interventions, and services. It was agreed that multivariate measures should be employed in assessing client gains rather than single progress measures.

A **second** concern voiced by conference participants was related to the funding of educational and social services for handicapped children and adults. Many conference participants felt that dollars should "follow the client" more closely than is currently the pattern of public support. Participants shared the assumption that reimbursement regulations and practices presently operate to maintain isolated and often non-functional service programs, and create disincentives to establish services, that are more cost-effective and consistent with prevailing philosophies of practice. One recommendation regarding this issue was to supplant the continuum funding system, based upon administrative settings, with innovative alternatives such as funding the costs of individual service plans using case managers as fiscal program agents. One recommendation was to adopt a voucher or contract system, whereby money would follow individual clients and families. It was also felt that financial resources could be more successfully combined by education and human services agencies at the local level.

The need for educating and providing training handicapped people in natural enviornments was a **third** area of concern raised by several groups. It was suggested that resources only be allocated to programs and practices that are consistent with the imperative of integration. There was general consensus among conference participants that there should be, and would be, a move away from debilitating institutional environments to less restrictive environments.

A **fourth** area of perceived need related to interagency coordination of services for handicapped children and youth. A crumbling of coalitions formed in the 1970s was predicted due to scarcity of resources and ideological schisms. Recommendations were made to improve interagency coordination of services by assigning a lead agency to assume primary responsibility during different stages of the individual's life cycle. The most appropriate lead agency would be designated according to the most pressing needs and agency emphasis for a particular phase of the client's development (e.g., prenatal, preschool, elementary school, high school, adulthood). This approach, it was felt, would foster more lifelong planning and comprehensive services. It still would do little, however, to solve existing problems, cited previously, that invariably occur across systems at critical stages in a person's or a family's life cycle.

A **fifth** cluster of recommendations was to more fully incorporate parents and handicapped persons themselves in program planning and evaluation. One group, for example, felt that national experimental studies and ongoing surveys of critical populations (parents, clientele, teachers, and other staff) should be conducted to provide feedback regarding educational and social services provided handicapped persons.

Other conclusions and recommendations were also generated as a result of the group sessions. Relative to status and anticipated trends, it was expected that there would be (1) improvement and expansion of technological innovations in services, (2) improved access to services, and (3) improved techniques to assess personal preferences of individuals with handicaps in designing service programs. On the less positive side, groups judged the state-of-the-art to be very weak in terms of assuring program quality, efficiency and effectiveness. It was also predicted that resource procurement for human services would at least decline relative to the cost of living in the next few years, producing some instabilities and discontinuities in services. It was speculated that problems would arise as a result of the movement from judicial remedies to legislatively mandated service changes. It was felt that the shift toward legislated changes in service programs might result in an increased focus on cost containment and lessen the emphasis upon achieving ideological imperatives of services for handicapped citizens.

A second task assigned to groups was that of making recommendations for improving research, development, demonstration, and dissemination efforts. One suggestion was to conduct more "ecologically valid" assessment, evaluation, and outcome research. The recommendation relating to ecologically valid assessment arose several times during the conference, as did the opinion that "ecological inventories" can be conducted to identify normal behaviors across different areas of curriculum or training. One group advocated that (a) funding be increased or reallocated for the purpose of improving community programs in order to promote increased direct care level employee retention and productivity, (b) that reimbursement strategies be developed for eliminating barriers to deinstitutionalization (such as eliminating the prohibition on pooling of funds), and (c) that methods be developed to improve evaluation of state-of-the-art practices and to translate research into practice. The establishment of experimental sites for researching decision making models for services which are based on client outcomes was also suggested.

Recommendations for improving policies, practices, and services generally paralleled those advanced for research and development. Exceptions were recommendations to employ behavior analysis techniques to understand and effect change in the organization of educational and human services, and to develop models for conducting cost-benefit analyses of service programs. One recommendation focused on the need for improving the distribution of information across different service systems. Given advances in technology and applications for handicapped persons, it was surprising that there were so few statements focusing on this topic.

The ideas generated through these discussions reflected a rather uncertain prognosis regarding the prospects for truly integrating services and handicapped citizens into society. Yet, members of the conference consistently identified salient problems of current service programs, and revealed remarkable consistency in proposing solutions. To improve the implementation of policies, changes were recommended throughout the service delivery system. Participants did not cite isolated problems, but rather seemed to identify broader relationships among policies, needed research and development efforts, regulations, public management, and provision of services. Starting with the need to reaffirm values and principles currently articulated in national and state policies, these recommendations argue for adoption of straight forward and feasible strategies for improving services and opportunity for handicapped citizens to develop to their maximum potential in normal settings. They further reinforce the realization that reform of services requires attention to many related issues to create the appropriate climate for effective and well managed service programs.

Conclusion

The fundamental principles underlying services for severely disabled adults will require far more than a simple fine-tuning of existing service programs. Reform and effective coordination of services begins with significantly changing the beliefs and expectations of many professionals about the value of integration and about the capacity of disabled people to benefit from it. Using services to promote increasing levels and types of community participation for disabled citizens should be not only a useful goal for services in general, but also be a highly relevant guide for the day-to-day objectives of program activities.

One of the persistent problems in service delivery today is that since systemwide goals and objectives, such as normalization, deinstitutionalization, and least restrictive placement are seldom interpreted or valued in the same way by all members, systems develop structures that permit ignoring them. Because activities of human service agencies are largely structured by their bureaucratic organization, in time the main focus of an increasing number of policies becomes maintaining a need for existing personnel and procedures. Policy decisions become increasingly related to compensating for unclear principles and objectives with standard operating procedures, finding new bureaucratic and programmatic problems to which old solutions, can be applied and generating new interpretations for no longer acceptable practices. There are many real vested professional and political interests in maintaining clear program and professional distinctions, and there are multiple sources of program funding that can be used as justification for human service feudalism. In fact, these forces, as they exist today, favor intensified competition, particularly among community services that are deeply affected by budget cuts as well as by difficult economic situations for educational and social service agencies in many states. All too often, the tendency among social services organizations is to respond to competitive pressures with political rather than programmatic tactics.

The need to improve service coordination for people with disabilities is a widely acknowledged problem. Its roots are grounded in the complex service needs of disabled people and their families, needs that clearly transcend traditional agency boundaries. Not surprisingly, our current service agencies admittedly seek increased degrees of specialization to perform their responsibilities. However, such trends in and of themselves are not inherently bad, and can often lead to improvement of service programs. Needed today, however, are the development of approaches to the needs of people which reflect standards of contemporary practice and address the multiple needs of individuals and families in a holistic manner, which includes current and longer range strategies.

Achieving more effective services must begin with a coherent **policy framework** that incorporates philosophical premises, goals and standards and consistent incentives to guide the ongoing management of service programs. More effective coordination of services, moreover, will require the adoption of joint planning and management approaches by largely autonomous agencies. Such efforts are more likely to succeed if they are approached as an interorganizational problem that requires careful analysis of resources and constraints, and if they include carefully developed joint action plans and a range of ad hoc management methods. An experimental project oriented strategy is more likely to successfully address the multiple needs of clients requiring joint agency actions than is simple reliance upon more generally constructed interagency agreements. Approaches that involve agreements are an important, but, only a limited approach to serious service coordination problems.

There are admittedly many remaining challenges in providing more effective and better coordinated service programs for adults with severe disabilities. But, there are also many recent positive signs of progress in our service programs. Perhaps more than ever, it is realized today that the problems with social services do not exclusively derive from inadequate resources. Increasingly, advocates and agencies of government are recognizing the need for service integration, the importance of values and the need to monitor results. This recognition, fueled by commitment to strategies stressing greater accountability, can provide the necessary impetus for needed changes in the management and operation of community service programs for adults with disabilities.

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Excerpts of Reviews and Comments

The following are excerpts of reviews, comments, and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as it relates to the content of Chapter Two by Robert H. Bruininks.

Dr. Bruininks speaks to the possible eventuality of total deinstitutionalization and comments suggest that community-based, smaller residential facilities will become the 'modus operandi' of the future. As a strong proponent for the least restrictive environment concept, I am, however, cognizant of the realism that every severely disabled person, whether physically, mentally or developmentally disabled, would not benefit substantially by the transition to community and/or work. Mr. Conley, in his chapter on Public Policies Obstructing Transition, takes a similar view when he states that the degree to which goals of independent living and/or rehabilitation can be achieved varies from person to person. First, the severity of disability and level of behavioral disorder are among the overriding factors that cannot be overlooked in determining the feasibility and appropriateness of a transition placement. Secondly, while we are making strides in terms of service provider consensus on the potential for, and client benefits to be derived from integration into community settings, we still have a long way to go in combatting community rejection and to reversing this rejection into support by way of continued public orientation and education

I concur fully in Dr. Bruininks' perception that the service components need to initiate a thorough examination of their values and commitment in regard to severely disabled persons. Before we can begin the necessary orientation to the various publics that should be involved if transition is to be a successful movement, consumers, parents, consumer advocates, educators and service providers must reach some common accord in relation to who and/or what it is we value in terms of habilitation and rehabilitation of severely disabled individuals. An expected result of such a value assessment would be the realization of a desired outcome -- commitment.

Recognition of what it is we value would then move us along in establishing goals and objectives to address those values. As an example, if I value, I will accept assignment and responsibility for the identified goals and objectives which will provide for, or be an impetus for change and/or improved services. The establishment of specific goals and objectives in a strategic planning framework exhorts involved participants to fulfill a stated obligation. Professional individuals and organizations are "success oriented." In other words, the service provider, whether it be parent, educator, habilitator or rehabilitator, will choose not to be the failure component in a cooperative arrangement. Strategic planning methods and outcome-oriented objectives have traditionally resulted in improved management which induces behavioral change and responsive service programming. While this is an "old" strategy it can be effective in a "new challenge."

Lastly, I must take issue with the recommendation or point of view taken in regard to the adoption of a "voucher or contract system." The position I take is that "vouchering" or "contracting" for individual client services relegates that client to a "number" rather than an individual. If our focus was merely on monetary gain or worth as in profit making organizations, or if our program mission was directly aligned with income maintenance, the vouchering proposal might be considered in a different light. However, if we value the "total person" and his/her worth we should continue as a client-based, individualized, service system which hopefully will provide and meet fully the integrated service needs of severely disabled citizens.

-- MIRIAM E. WALKER

Dr. Bruininks and colleagues have cited many of the existing barriers and contribute to the problem of unauthorized and inadequate public services for disabled citizens. Developing more effective strategies for developing and implementing public policies to bring about the necessary reforms will be the greatest challenge human service providers will be facing in the next ten years. The actions suggested in this paper can provide direction toward more accountable services.

All members of our communities must be made aware of the unfulfilled promises made to parents and families of severely handicapped children over the past 15 years. Parents and families were encouraged to keep their children at home with the implied promise of community services from "cradle to grave." With the growing realization that public education is the only service systems with a zero-reject mandate, their is a growing hostility toward those of us who advised against institutionalization. Families are questioning our advice and are starting to indicate that institutionalization would have been a **better option** because of the lack of services available to individuals aging-out of public schools programs. These feelings are further reinforced when parents and families learn that first priority for community-based adult services has been given to the institutionalized population.

Those of us who were responsible for making these implied promises should be compelled to commit ourselves to advocating for the reforms necessary to build the continuum of services for handicapped adults in our communities.

-- WILLIAM HALLORAN

Switzer
Scholar
Conley

Chapter Three

Public Policies Affecting Transition From School to Independence: Removing the Barriers

By Ronald W. Conley

System of Services

There are numerous programs that provide services and financial support to disabled persons. Some of the more important of these programs are as follows:

Income Support

- The Social Security Disability Insurance (SSDI) program provides income support to disabled workers who qualify on the basis of a substantial work injury.
- The Childhood Disability Beneficiary (CDB) program is part of the SSDI program and pays income support to disabled adults (age 18 or over) whose disability began before age 22, if these persons qualify as a dependent son or daughter (or an eligible grandson or granddaughter) of a retired, deceased, or disabled worker. The rules governing this program are the same as for the SSDI program.
- The Supplemental Security Income (SSI) program pays income support to disabled persons who are not covered by the Social Security program (or who receive SSDI/CDB benefits that are lower than the SSI benefits) and who have extremely limited assets.
- Other programs paying income support are the Railroad Retirement program and Federal and State civil service programs.

Health Care

- The Medicare program pays health benefits to disabled SSDI/CDB beneficiaries after they have received SSDI/CDB benefits for two years.
- The Medicaid program provides health benefits to disabled and aged persons who do not qualify for Medicare and who have extremely limited assets. Almost all SSI beneficiaries also qualify for Medicaid.

Employment Programs

- The State-Federal vocational rehabilitation programs fund vocational services to qualified disabled persons.
- The State employment services assist disabled persons to locate suitable employment.
- The Targeted Jobs Tax Credit program gives employers a tax credit of 50 percent of earnings up to $3,000 for the first year for each disabled person that they hire, and a credit of up to $1,500 during the second year.

- The Job Training Partnership Act provides Federal funds so that States can provide a wide range of services to economically disadvantaged persons and others who face serious barriers to employment.

- The State employment services assist persons, including disabled persons, to locate suitable employment.

Housing

- The Intermediate Care Facilities for Mentally Retarded (ICF/MR) persons program, a component of the Medicaid program, funds residential care and other needed services to persons with mental retardation and related conditions. To qualify, mentally retarded persons must meet income and asset tests and be in need of 24-hour-a-day care.
- The Department of Housing and Urban Development maintains a rent subsidy program for low income persons who reside in public housing.

Education

- Almost all disabled children have access to a free public education, regardless of the severity or type of disabling condition.

Social Services

- The Administration on Developmental Disabilities funds a number of activities that are intended to improve services to developmentally disabled persons. Developmentally disabled persons are severely disabled persons whose disability began before age 22.

State and local social service agencies provide a variety of social services, partly supported by the Federal Social Services Block grant.

This is an incomplete listing of programs which provide or fund services to disabled Americans. Some programs, such as those funded by the Veteran's Administration and by Federal and State workers' compensation programs do not fit neatly into the above generic classification of services. In addition, there are many private programs funded or operated by employers and nonprofit organizations (such as the Association for Retarded Citizens) that provide services to disabled Americans. Finally, we should include public programs that provide services to persons with chronic mental illness, or to aged persons (some of whom are disabled).

At a point in time, a disabled person may be receiving benefits from numerous programs. For example, many people receive SSDI/CDB as well as SSI, Medicaid, and Medicare. A few of the individuals will also receive food stamps, rent subsidies, vocational rehabilitation, and social services.

These various programs must be viewed as comprising a system of services to disabled Americans. In assessing disability policy in the United States, it is the combined and interacting effects of these programs on disabled persons that is relevant. This is not only because disabled persons often require multiple services, but also because failure in one program may be due to the effects of other programs, e.g., the failure to rehabilitate a disabled person may not be due to the inadequacies of the rehabilitation agency, but to work disincentives in the income support and health care financing programs.

Social Goals

During the last twenty-five years, there have been revolutionary changes in the goals that are regarded as desirable for severely handicapped Americans, particularly persons who are chronically mentally ill or severely mentally retarded. Where the term "severe disability" used to be virtually synonomous with "total dependency," it is now recognized that most severely disabled people can be partly or totally self-sufficient if provided with appropriate services. In particular, they are capable of: learning and developing their academic, vocational, and social skills; living in community-based residences, sometimes with, and sometimes without protective supervision; participating in community activities such as eating in restaurants, shopping, visiting friends, using public transportation; and engaging in substantial work.

Of course, the degree to which disabled Americans can achieve these goals varies markedly from person to person depending upon the nature of their disability and its severity. Even more importantly, it depends upon the availability and appropriateness of services and support.

Obviously, without appropriate and extensive educational and developmental services as children, few severely disabled people will achieve meaningful independence as adults. In 1975, Congress enacted the Education for All Handicapped Children Act which required participating States to furnish all disabled children, regardless of the degree of their disability, with a free and appropriate public education. As a consequence, large numbers of severely disabled children who were previously not being provided with an eduation or who were being served inappropriately (United States Commission on Civil Rights, 1983) entered into the public school system. Children who might otherwise be institutionalized now remain with their families, who share the substantial, and sometimes emotionally difficult, task of preparing them for adult life.

The expectation of these families is that, as adults, severely disabled persons will be able to live in the community in the least restrictive and most normalized manner, e.g., participate in community activities and engage in substantial employment, usually in regular work sites. It would be reasonable to expect that the service system for adults would be supportive of these goals. As will be discussed in the next section, however, the service system creates major obstacles to the attainment of normalized community life.

Obstacles to Transition from School to Independence

1. **Work Disincentives:** An overwhelming proportion of the resources expended by the service system for disabled persons is used to fund cash transfers and pay medical bills. Berkowitz (1985) estimated that 97 percent of total public and private expenditures on disabled persons were used for these purposes.

With few exceptions, these income support and health care financing programs create major work disincentives. In large part, they create these work disincentives because of a fundamental misconception about disabled persons. This misconception is the belief that disabled persons can be evaluated and neatly divided into those that are capable of substantial gainful activity (SGA) and those who are not. In order to qualify for SSDI/CDB, SSI, Medicare, or Medicaid, most disabled persons must be believed to be incapable of earning at a SGA level. There is not a one to one relationship between SSI and Medicaid because some states maintain more restrictive conditions for eligibility for Medicaid than exists in the SSI program and because some persons may qualify for Medicaid as medically needy in states which maintain a medically needy program. Many private disability programs utilize the Federal definition of disability (Schwartz, 1980) which incorporates this fundamental misconception. Persons who are blind have much less restrictive eligibility requirements for these programs.

At present, both the SSDI/CDB and the SSI programs define a person as capable of earning at a SGA level if they can earn $300 or more per month, a level that has not been changed since 1979. For a full time worker, this SGA level is the equivalent of about 60 percent of the federal minimum wage. The SGA level for blind persons is over twice this amount.

There are two problems with this criterion of eligibility for SSDI/CDB and SSI. First, it assumes that a reasonably accurate technology exists with which to determine who is not able to work at a SGA level. Few persons who work with severely disabled adult persons agree that current vocational assessment methods are reliable. In fact, current techniques for assessing a disabled person's vocational potential can be quite misleading (McCrary & Blakemore, 1985). The enormous percentage of permanent disability cases litigated in workers' compensation (Conley and Noble, 1979) and the high percentage of appealed cases among denied applicants to SSDI/CDB and SSI further attest to the uncertainty and unreliability of evaluations about work capacity.

The second problem with the eligibility criterion is that it overlooks the great difficulty that many disabled people encounter in locating work if they lose their job for some reason (e.g., because of cyclical unemployment, automation, employer bankruptcy). During this difficult and sometimes prolonged time, severely disabled workers may be denied the income support and health care financing benefits that they need while searching for, and perhaps being trained for, another job.

Work disincentives arise from two major causes--the net gain or loss that disabled people incur, and the probable reduction in the security of income and other benefits that they face, as a consequence of accepting substantial employment.

Net Gain from Work: To measure the net gain or loss from returning to work, we must aggregate the value of all of the program benefits that must be given up by disabled persons. Most people receiving public benefits receive benefits from more than one program. For example, about 38 percent of all beneficiaries of the Childhood Disability Beneficiary Program are concurrent recipients of SSI (Social Security Administration, 1984). In addition, during 1982, over 91 percent of SSI recipients also received Medicaid benefits, 46 percent received food stamps, 12 percent received school lunches, and 15 percent were in public housing (Congressional Research Service, 1984).

Although our subsequent discussion will separately examine the SSDI/CDB, SSI, Medicare, and Medicaid programs, it must be kept in mind that the individual effects of these programs are usually only a part of the work disincentives facing beneficiaries.

The potential for reducing work incentives is particularly strong in the SSDI/CDB program. Under current law, SSDI/CDB beneficiaries who accept substantial work are entitled to a nine month trial work period. At the end of the trial work period, the beneficiary is re-evaluated and if he or she is found capable of earning $300 or more per month, after deduction of extraordinary impairment-related expenses, then benefits are terminated.

In order to determine the net gain (or loss) among beneficiaries who lose their entitlement to benefits, the following deductions must be made from their earnings.

- The benefits formerly received from the SSDI/CDB program. Theoretically, these benefits may exceed $2,000 per month in the case of families, and $1,000 per month in the case of individuals. Of course, the great majority of beneficiaries receive far less. During the first quarter of 1985, the average monthly payment for disabled workers was about $430.
- Any income taxes that must be paid. In almost all cases, these will include Social Security and Medicare taxes of approximately 7 percent in addition to Federal and possibly State and local taxes. Since Social Security and SSI Benefits are not taxable, it requires earnings greater than these benefits to provide a net income equal to these benefits.
- Any work-related expenses, such as special clothing costs, transportation, lunches, child care, etc. Normal work expenses are sometimes substantial, particularly in the case of disabled parents who must pay for child care in order to return to work.

Clearly, the disincentives to work can be substantial. In some cases, the benefits under SSDI/CDB actually exceed the amount that disabled beneficiaries can earn, even though these earnings are sufficient to cause benefits to be terminated.

Potential work disincentives are less dramatic in the SSI program. In determining the monthly benefits to be paid to SSI beneficiaries, the following steps are followed:

- The first $20 of earned or unearned income and the next $65 of earnings are exempt from consideration.
- The amount of any extraordinary impairment-related work expenses are deducted from earnings.
- Thereafter, benefits are reduced by $1 for every $2 of earnings over these exempted amounts. Benefits are reduced by $1 for each $1 of unearned income over the exempted amount ($20).

In 1986, the basic SSI benefit for an eligible individual is $336 per month and $504 for an eligible couple. At these levels, all Federal SSI payments will cease when earnings reach about $757 per month for a single individual (without any non-earnings income) and $1,093 for an eligible couple.

Prior to 1981, an SSI recipient who began to work on a substantial job would be placed on a nine month trial work period. At the end of the trial work period, the recipient would be re-evaluated and if found capable of earning more than the SGA level, SSI payments would cease.

Let us consider two cases based on the benefit levels which exist in 1986, but apply the rules governing benefits which existed prior to 1981. The first case involves an SSI recipient who accepts a job paying $250 per month and the second relates to an SSI recipient who accepts a job paying $350 per month. At the end of the trial work period, the higher paid person would lose the entire $336 SSI payment and end up with a net increase in gross income of only $14. The worker making $250, on the other hand, would still receive an SSI payment of $253 per month and end up with a gross income of $503 per month. The lower earning recipient would actually end up with almost $153 more per month than the higher earning recipient.

Clearly, it would be to the benefit of a SSI beneficiary to choose the job paying the lesser wage if possible. It is doubtful if a knowledgeable beneficiary would accept the higher paying job, particularly since taxes and normal work expenses would also have to be paid. Of course, even if the beneficiary chose the lower paying job, the Social Security Administration could re-evaluate the person and terminate benefits on the grounds that he or she was capable of earning over $300 per month.

Recognizing these problems, Congress authorized a special three year demonstration program beginning on January 1, 1981 (incorporated as Section 1619(a) of the Social Security Act) which permitted working SSI beneficiaries to continue to be paid SSI benefits beyond the trial work period as long as their earnings were below the Federal breakeven point, based on a $1 reduction in benefits for each $2 in earnings (and disregarding the first $20 of income from any source and the next $65 of earnings). The recipient making $350, for example, would continue to receive an SSI payment of about $203 and his or her gross income would be about $553 per month, an increase of about $218 in gross income over the benefit amount without working. This special demonstration has been extended to June 30, 1987.

The above calculations are based on the receipt of Federal SSI benefits only. About half of the States supplement Federal SSI payments. These supplements usually increase work disincentives by an amount that depends upon the size of the supplement and State practices, e.g., some States terminate the entire supplement when Federal benefits end, while other States continue the $1 reduction in benefits for each $2 in earnings.

Continuation of health benefits is often as important, and sometimes more important, to disabled persons as continuation of income payments. Medical expenditures are frequently unpredictable, and sometimes very large. For some beneficiaries, the value of health benefits exceeds the value of SSI or SSDI/CDB income support. Unfortunately, some SSI and SSDI/CDB beneficiaries who return to work are unable to obtain health care coverage as a fringe benefit where they work or privately because insurance companies often do not cover people with certain types of pre-existing conditions. Other persons are unable to afford the high private insurance premiums charged to persons who are in less than perfect health.

What happens to Medicare benefits if SSDI/CDB beneficiaries return to work? Prior to 1981, a return to a job paying the SGA wage or more led to termination of cash benefits and loss of eligibility for Medicare after a trial work period. During 1980, however, Congress changed the law so that SSDI/CDB beneficiaries could continue to receive Medicare coverage for 36 months after a determination that the beneficiary is capable of working at a SGA level. In addition, Congress eliminated the 24 month waiting period for Medicare coverage in the case of former SSDI/CDB beneficiaries who become re-entitled to SSDI/CDB benefits within a five year period after cessation of cash benefits.

What happens if SSI beneficiaries who receive Medicaid return to substantial work? Prior to 1981, many beneficiaries who lost their eligibility for SSI also lost their Medicaid coverage. In 1980, Congress authorized a three-year demonstration program (incorporated as Section 1619(b) of the Social Security Act) to provide continued Medicaid coverage to SSI beneficiaries who return to substantial work even if their income is too high to qualify for Federal SSI benefits. In order to qualify for this program, it was stipulated that the recipients must: (a) continue to have a disabling condition; (b) have difficulty maintaining their employment without medical coverage; and (c) lack earnings high enough to pay for benefits equivalent to the combined value of Federal and State SSI payments and the Medicaid coverage that they would have continued to receive. This demonstration has been extended to June 30, 1987.

Security of Income: People make decisions about when and where to work (or whether to work at all) not only on the basis of the amount that they can earn, but also on how secure a job is. People will often forego a higher paying but less secure job to remain in employment that is protected by union rules, seniority provisions, tenure, civil service, or has some other type of buttressing against the swings of the business cycle.

The desire for income security creates a strong work disincentive among beneficiaries of public income support and health care programs. Why should we expect that beneficiaries of these programs will easily give up what appears to be a secure monthly cash income and assured medical care in exchange for jobs that are often temporary or insecure (and that may pay little more, or even less, than their monthly benefits).

Recent changes in the Social Security Act serve to reduce the fear that beneficiaries who return to work might have about the loss of their job. For both the SSDI/CDB program and the SSI program, the 1980 Amendments provided for a 15 month re-entitlement period following the trial work period and a determination that the beneficiary is capable of working at a SGA level. In addition, the extension of Medicare coverage for 36 months after cash benefits cease and the elimination of a second 24-month waiting period for Medicare for persons who become re-entitled to SSDI/CDB benefits within five years should also reduce the insecurity of beneficiaries who return to work.

Specific Work Disincentives: Despite these changes in the laws governing the Federal income transfer and health financing programs, many work disincentives remain. Those affecting the net gain from work are as follows:

(a) We have already described the reasons why many beneficiaries who return to work may end up with a relatively small increase in their standard of living. In some cases, living standards will actually decline.

(b) Despite the availability of Section 1619(b) benefits, some SSI beneficiaries who return to work will lose their entitlement to Medicaid benefits. According to Social Security regulations, SSI beneficiaries are eligible for extended Medicaid benefits under Section 1619(b) if their income is below a threshold amount. This threshold amount differs from State to State and is equal to the Federal breakeven amount (calculated on an annual basis) to an individual living in his or her own household plus two times the State supplement for one year plus the average Medicaid expenditure for disabled SSI beneficiaries in the State. In 1984, this threshold amount varied from $8,500 to $21,500. If the earnings of an individual exceed this threshold amount, the Social Security Administration checks to see if actual or anticipated Medicaid expenditures for the individual are higher than the State average. If they are greater, then these higher Medicaid expenditures, rather than the State average expenditure, are used to calculate the threshold amount for the individual. Two problems exist with these threshold amounts. First, there are obvious inequities among States. More importantly, important work disincentives will continue for SSI beneficiaries whose income exceeds the threshold amount, but who cannot obtain medical insurance privately or as a fringe benefit because of their condition. Even though they may not be incurring immediate medical expenses, the threat of major future medical expense remains.

Some SSI beneficiaries will lose their entitlement to Section 1619(b) benefits for another reason. Current regulation stipulates that a beneficiary who did not file a Medicaid claim during the previous year and does not expect to do so during the coming year will not be entitled to Section 1619(b) coverage on the grounds that they do not need such protection in order to work.

(c) Federal regulations governing reimbursement for care in Medicaid approved facilities may have an overwhelming effect on work incentives since they create a nearly 100 percent tax on earnings. These regulations stipulate that the Federal payment made to these facilities must be reduced by any amount of income in excess of a personal needs allowance which may be as low as $25.

The following specific work disincentives may reduce the security that beneficiaries who return to work feel in terms of the security of their income.

(a) The 15 month re-entitlement period for SSDI/CDB and SSI may not be sufficiently long to allay the fears of some beneficiaries.

(b) Some SSDI/CDB beneficiaries may be concerned about the loss of Medicare benefits that will occur three years after they lose entitlement to cash benefits.

(c) Some SSI beneficiaries may fear that Congress will not indefinitely extend the Special Cash Benefits and the Special Medicaid demonstration projects (Sections 1619(a) and 1619(b). In fact, there was a nine month period between the time the authority for the initial three-year demonstration projects ended and the time at which it was renewed.

(d) Beneficiaries may fear that engaging in substantial gainful activity for an extended period of time may lead to the finding that they are no longer disabled if their case is reevaluated and that they would then no longer be eligible for SSDI/CDB benefits, regular SSI benefits, or even Section 1619(a) benefits, especially if there is evidence of medical improvement. This fear is quite justified since earnings above the SGA level are a specific indication that the case should be reconsidered. Moreover, some cases are slated for periodic reevaluation because medical improvement is expected. If their cases are reevaluated, SSI beneficiaries may find they are no longer eligible for either regular or Section 1619(a) benefits by virtue of their earnings above the SGA level.

Even beneficiaries who are reevaluated after losing their jobs may have their benefits terminated if they are reevaluated unless they can show that their job loss was due to their disability. If, however, their job loss is due to factors such as cyclic swings of the economy, technological change, loss of business by the employer, or any of a number of reasons that also cause non-handicapped workers to lose their jobs, then the worker will probably lose his or her entitlement to benefits. Despite the fact that the beneficiary has shown a capacity to earn the SGA wage under certain circumstances, it may be a long time, if ever, before he or she can find another job.

(e) The Social Security Administration has interpreted Section 1619(a) to mean that after the trial work period and a fifteen month reinstatement period, a person is eligible for a special SSI benefit only if he or she received an SSI cash benefit during the previous month, either a regular SSI benefit, a Section 1619(a) benefit, or a State supplement. Similarly, a person continues eligible for Section 1619(b) only if he or she received, or was eligible for, a SSI benefit, a regular Medicaid benefit, or a 1619(b) benefit during the previous month. The fifteen month reentitlement period begins to run after the trial work period even though the beneficiary continues to receive Section 1619(a) benefits so that after 24 months of accepting substantial work, no reentitlement rights remain (assuming the beneficiary had a full nine month trial work period remaining when he or she accepted substantial work).

If a beneficiary who is no longer entitled to reinstatement does not receive an SSI benefit during the previous month, then he or she loses the program connection and all SSI benefits including Section 1619(a) benefits. The person may reapply for SSI benefits, but only for the basic program, not for Section 1619(a) benefits. In these cases, the former beneficiary must be evaluated as too severely disabled to earn the SGA wage in order to be declared eligible for any SSI benefits, a virtual impossibility for someone who has been receiving Section 1619(a) benefits because he or she has been earning above the SGA level, and sometimes even above the Federal breakeven point if the State pays a supplementary benefit. Similarly, a person who becomes ineligible for a Section 1619(b) benefits also loses the program connection and must be recertified as eligible for the basic SSI program before further benefits can be provided.

These administrative provisions can result in capricious loss of benefits, substantial hardships, and major inequities. As examples:

- Section 1619(a) beneficiaries can lose entitlement to special SSI cash benefits because of a relatively small one time gift or bequest, often less than $300, or a year end work bonus, or even an unusual amount of overtime work.
- If an individual accidently saves more than $1700 ($2550 for a couple), he or she may lose entitlement to both Section 1619(a) and Section 1619(b) benefits. These asset limitations are those existing in 1986.

Several other problems in the income support and health care financing programs which may impede the employment of severely disabled persons merit attention.

(a) Not everyone receiving SSI is automatically entitled to Medicaid or Section 1619(b) benefits. Twenty of the States in early 1985 used their own definition of who is entitled to Medicaid benefits. In consequence, some persons receiving SSI may not be entitled to Section 1619(b) benefits.

(b) The intent of the trial work period is sometimes nullified since any month in which the earnings of beneficiaries are $75 or more must be considered part of the trial work period. Moreover, the trial work period need not be continuous and only one trial work period is allowed per worker. Sometimes the trial work period is exhausted while beneficiaries are in sheltered workshops, before they have an opportunity to test their ability to work on regular jobs.

(c) Significant inequities arise because benefits from the Section 1619(a) and Section 1619(b) programs are available only to persons who have established eligibility for SSI benefits by convincing a disability determinations unit that they are incapable of working at an SGA level. Not only does this create work disincentives for persons not yet receiving SSI, but it also results in obvious inequities if some handicapped individuals receive Section 1619(a) and 1619(b) benefits while others do not, even though they have the same earnings.

(d) Finally, the breakeven point at which a beneficiary loses entitlement to SSI may be considerably lower if the individual is also entitled to both SSDI/CDB and SSI benefits. As a consequence, serious inequities may result and possibly substantial work disincentives.

Consider a case where a beneficiary receives $300 from SSDI and $45 from SSI. Suppose the beneficiary accepts a job paying $250 per month. The SSI benefit will be terminated. Total income will be $550 ($300 + $250). But suppose the beneficiary subsequently obtains a "merit" increase to $350 per month. After the trial work period, he or she is reevaluated and found not eligible for SSDI/CDB because earnings are above the SGA level. Total income declines to $350. In contrast, a person who was never eligible for SSDI/CDB and who had the same job history would end up with a total income of $552 under Section 1619(a) - $350 in earnings and $202 in SSI benefits.

(e) In determining whether a person's earnings constitute substantial gainful activity, extraordinary impairment-related work expenses are deducted from earnings, both for applicants to, and beneficiaries of, the SSDI/CDB program. Extraordinary impairment-related expenses are also deducted from the earnings of SSI beneficiaries in determining the benefits they receive. However, they are not deducted from earnings when evaluating the eligibility of applicants to SSI which not only creates inequities, but may discourage some disabled persons from seeking work.

Blind Beneficiaries: Persons who are blind receive much more favorable treatment from the income transfer programs than persons with other disabilities. For blind persons who receive SSDI/CDB, the SGA level is $650 (1986) and is adjusted upward annually to reflect changes in the cost of living. Blind persons who apply for or receive SSI are not even subject to a SGA determination. Eligibility is based solely on the existence of a medical condition.

The benefits of employed SSI beneficiaries who are blind are reduced by the same formula as for other SSI beneficiaries with one exception. Extraordinary impairment-related work expenses are deducted from what would otherwise be the deduction in the SSI payment as a result of earnings, instead of from earnings as is done for other beneficiaries. The effect of this is that the SSI program pays the full cost of these expenses for blind beneficiaries, and only 50 percent of the cost for other beneficiaries.

In the case of persons who are blind, SSI benefits continue as long as earnings and other income are below the point at which all benefits are offset. Thus they have the same benefits as other disabled beneficiaries under Section 1619(a). Unlike other SSI beneficiaries, if no benefits are payable, blind persons are not reevaluated to determine if they are still disabled. Instead, benefits are suspended and resumed if income declines to a point where benefits are again payable.

2. **Fostering of Dependency Attitudes:** The pro-

cess of establishing eligibility for the income support or health care financing programs creates habits and attitudes of dependency that may never be changed. The process may last from two months to a year and during that entire period applicants are impelled by the system to prove that they are unable to engage in substantial work. Efforts to return to work or the acceptance of vocational rehabilitation services are likely to result in a finding that the applicant is not eligible for public income support or health care financing and applicants are often advised against such activities.

Assistance in documenting work disability is usually obtained from vocational specialists, doctors, lawyers, social workers, family, friends, and others. Is it any wonder that the process convinces applicants of their inability to work and the folly of attempting to work? In this regard, it is noteworthy that one study of workers' compensation shows that claimants who do not need to prove the extent of their injuries generally fare better in employment than claimants with comparable injuries who become involved in litigation over the extent of their work disability (Ginnold, 1984).

3. **Disincentives to Save:** In order to qualify for SSI or Medicaid, applicants for benefits can possess a home, automobile (with some limitations), burial plot, some insurance, personal effects, and no more than $1600 in cash, savings accounts, and other liquid resources for an individual and $2400 for a couple. In 1984, about 20 percent of the persons applying for SSI were turned down because of excess resources and about 65,000 beneficiaries were terminated because of excess resources (Social Security Administration, no date). In consequence, in order to qualify for benefits, disabled persons must spend down into poverty, and in order to continue to be eligible for benefits, disabled persons must spend most of what they receive. Although most SSI beneficiaries save very little, there are a few who manage, or would manage, to accumulate an amount in excess of the stipulated amounts if they were not discouraged from doing so. As increasing numbers of beneficiaries begin to receive Section 1619(b) benefits where earnings range between $9,000 and over $20,000 per year before losing entitlement to all benefits, this asset restriction is likely to become increasingly important to beneficiaries. It clearly is non-normalizing to place such stringent restrictions on savings.

4. **Institutional Bias of Medicaid Program:** Many severely disabled persons have difficulty obtaining appropriate community-based residential care. The primary source of Federal funds for residential care is the Medicaid program. The Intermediate Care Facilities for Mentally Retarded (ICF/MR) persons program, a component of Medicaid, provides basic shelter and comprehensive services to persons with mental retardation and related conditions. Persons can be placed in an ICF/MR for purposes of receiving either health care or habilitation services. In June, 1982, there were about 140,000 occupied beds certified for ICF/MR reimbursement (Bruininks, 1985).

Initially, the ICF/MR program was used almost exclusively to support large State institutions for persons with mental retardation. Since the ICF/MR programs was started in 1971, however, there has been an increasing emphasis on the use of small community-based residences. Nevertheless, by 1982, there were fewer than 10,000 occupied ICF/MR beds in facilities with 15 or fewer residents (Bruininks, 1985). Overall, there were about 64,000 mentally retarded persons living in State licensed residential facilities for mentally retarded persons with 15 or fewer persons in 1982 (Bruininks, 1985). This figure includes persons living in ICFs/MR and other types of facilities. Overall, there were 244,000 mentally retarded persons residing in facilities licensed to provide care to mentally retarded persons.

Even among residents of small ICFs/MR, there is a strong bias toward the provision of institutional type care. In order to qualify for the ICF/MR program, residents must be in need of 24-hour-a-day care. In consequence, residents placed in ICFs/MR have little prospect of employment in integrated settings and, the opportunities for meaningful integration into community life are sharply limited. Lacking clear criteria as to the characteristics of individuals who need 24-hour-a-day care, States have substantial latitude in placing persons in ICFs/MR and a strong financial incentive to do so. In consequence, some residents may be kept in more restrictive conditions than would otherwise be the case.

Recognizing these problems, Congress passed the Home and Community-Based Services Waivers program in 1981 to enable States to provide services in the community to persons who would otherwise be placed in institutional care. In 1985, about 20,000 mentally retarded persons were receiving services under this program. In principle, this program could greatly reduce the institutional bias in the Medicaid program. However, it is severely limited since it can only serve persons who could have been placed in institutional care. In effect, the State must demonstrate that empty institutional beds exist into which these persons could be placed or must show that new institutional beds would have been created.

Adult working age persons with disabilities other than mental retardation can obtain residential care funded by Medicaid only if they are admitted to a health oriented skilled nursing facility or intermediate care facility. It has been argued that large numbers of persons with mental illness and some severely physically handicapped persons have been placed in these facilities rather than in less restrictive community-based care in order to obtain Federal reimbursement for their care.

5. **Lack of Long-Term Vocational Services:** Many severely disabled persons leaving school will require long-term, and perhaps life-long vocational support in order to work in supported employment in integrated settings. Unfortunately, these services are frequently unavailable forcing these persons to either accept inappropriate services or not to receive services. Buckley and Bellamy (1985) conducted a survey of day and vocational programs for adults supervised by developmental disability or mental retardation agencies. They reported that of slightly over 185,000 persons served, 73 percent were in adult day programs, 24 percent were in sheltered workshops, and only 3 percent were in integrated work settings. The majority of the programs are not designed to promote independence.

There are at least three reasons to explain this severe lack of long-term employment services. The first reason is that vocational rehabilitation agencies generally emphasize time-limited services. By and large, the success of counselors is measured by the number of successful closures. In consequence, although the vocational rehabilitation program has legislative authority to provide long-term follow along services to clients, relatively few clients have been served under this authority. In general, counselors have an incentive to avoid difficult cases that have a low probability of a successful closure or which will require a great deal of counselor time. Congress has attempted to counter this bias by requiring that priority be given to serving persons with the most severe handicaps. However, the definition of who can be rehabilitated is judgemental and persons needing long-term vocational services are not yet effectively served by vocational rehabilitation agencies.

The second reason for the preponderances of adult day care programs for mentally retarded/developmentally disabled persons is that Medicaid regulations for both the ICF/MR and (until 1986) the Home and Community-Based Services Waivers programs specifically prohibit the use of Medicaid funds to provide vocational training (CFR 441.13(b)). However, since active treatment must be provided if persons are to remain eligible for the ICF/MR program, the States often place these clients in non-vocationally oriented day activity programs for which they may receive Medicaid funding. This prohibition was slightly relaxed by the Consolidated Omnibus Budget Reconciliation Act of 1986, which permitted supported work and other vocational programs to be funded by Medicaid to persons leaving institutional care to be served under the home and community-based services wavers program.

A final reason for the limited availability of services to provide mentally retarded adults with jobs in integrated settings is that the concepts of supported work (i.e., that which requires lifelong services) and transitional services (i.e., that which requires long-term, but time-limited services) are relatively new and still in the process of development. Undoubtedly, the number of persons in these programs will rise dramatically during the next few years. Nevertheless, it is important to remember that there are almost no financial incentives for a State to provide these services, and substantial financial incentives for a state not to provide them.

6. **Coordination problems:** The difficulty that severely disabled persons often encounter in accessing needed services in a timely manner is often referred to as the coordination problem. There are a number of reasons for the failure to coordinate services:

First, there are many different programs from which disabled individuals might receive services - SSDI/CDB, SSI, Medicaid, Medicare, HUD rent subsidies, public housing, social services, school lunches, Aid to Families with Dependent Children, etc. For the most part, these programs are separately administered. Few severely disabled persons are even aware of all of these programs (or their complicated eligibility requirements). Even if they are aware of these programs, problems may arise because separate applications must be made to different agencies in diverse locations.

Second, despite the obvious need to do so, the individual parts in the service system do not operate as an entity with clearly articulated parts which move cooperatively and efficiently to achieve social goals. For the most part, these programs are managed independently of each other, and each has its own set of goals, priorities, eligibility requirements, and operating procedures. Program managers tend to be quite unconcerned as to whether these goals, priorities, eligibility requirements, and operating procedures support or interfere with those of other programs.

A third problem in coordinating these programs is that some programs are managed at a Federal level (e.g., SSDI/CDB, SSI, and Medicare) other at the State level (e.g., vocational rehabilitation, Medicaid), and yet others at the local level (e.g., some social service and housing programs).

Finally, a major reason for the lack of coordination among the different programs is that the system of services for disabled people does not have a set of consistent and uniform goals for disabled clients that each of its individual programs are expected to support. Instead, the programs tend to have limited programmatic goals, such as providing income support, which may interfere with the achievement of other goals, such as employment. More than any other reason, the lack of consistent and uniform goals explains why the system often performs in a fragmented and counterproductive manner.

Some examples of the consequences of this lack of coordination are:

- Bradley, et. al. (1978) reported that "Some disabled persons have reportedly been denied SSI benefits on the grounds that their disability was not sufficiently severe and yet have been denied VR services because their prognosis for employment was too poor."
- It is often alleged that workers' compensation cases that are in litigation are discouraged by both their lawyers and by VR counselors from taking part in rehabilitation programs - in the first case because it would weaken their claim in court, and in the second case because it is feared that workers' compensation cases would not be highly motivated to be successful in the rehabilitation effort.
- Similarly, social workers who have managed to obtain the security of an SSI check for their clients with which to pay basic living costs may be reluctant to jeopardize this secure income in favor of less secure earnings.
- A striking example of how a public program may fail due to lack of program coordination arises from the periodic reviews required by SSDI and SSI. These reviews are required every three years to confirm continuing eligibility for these programs. Such reviews could be a powerful and desirable means with which to encourage people to return to work. Yet, implementation of these reviews has led to tragic results.

What is wrong with these periodic reviews? The basic problem is that they fail to take account of the fact that the functional limitations of most seriously handicapped persons often make it difficult for them to locate work, may result in prolonged periods of joblessness, and may cause profound discouragement, regardless of whether or not they are believed capable of earning the SGA level of $300 per month. Even though many SSI and SSDI/CDB beneficiaries are capable of working at an SGA level, they often need extensive assistance, assurance, and a considerable period of preparation before they are likely to find substantial work.

If the transition to work is to be effective, it must take place gradually, not abruptly. Unfortunately, the present periodic review procedures do not permit a gradual transition to work. Beneficiaries are notified that they are capable of substantial work and thus no longer eligible for income support. Little or no provision is made to assist them to find gainful employment or to refer them to agencies that will provide the services needed to enable them to return to work.

Although the 1984 Amendments to the Social Security Act will require continuation of benefits during the appeals process, this will, if anything, further reduce work incentives since beneficiaries who appeal will continue to attempt to prove their complete incapacity for work.

7. **Other Service System Problems:** Two other problems in the service system which impede the transition from school to independence merit mention.

The first problem is the limited and fragmentary information about the social adjustment of disabled persons and the services provided to them that exists at the Federal level. Lacking a comprehensive data system, the push to create a more effective service system is greatly impeded.

For example, despite the long-standing emphasis on placing severely disabled people in community-based residential care, little information is available on the number of persons residing in various forms of community residences, particularly persons with severe physical disabilities or mental illness. Although researchers at the Center for Residential and Community Services at the University of Minnesota have collected extensive information on residences licensed to care for persons with mental retardation, there is no assurance that this data base will be continued over time. Similarly, there is little data in such areas as the methods of employing severely disabled people or the provision of family services.

Without such information, policy is often developed on the basis of intuition and hunch rather than a careful assessment of existing problems, their causes, the number of people affected, and options for resolving these problems.

The second problem refers to the distorting effects of Federal funding policies. A large part of the service system is financed by Federal funds. In most cases, the Federal government establishes rigid rules which must be complied with in order for State governments to be reimbursed for services.

State and local legislators have a strong fiscal incentive to shift as large a part of the cost of operating the service system to the Federal government as possible, a goal that often conflicts with attaining the most desirable goals for clients. Thus, many mentally retarded persons are placed in ICFs/MR, even though less restrictive residential care would be more appropriate. Disabled persons seeking help from social services agencies are assisted to obtain SSI even though this greatly inhibits the likelihood of subsequently engaging in work. Mentally retarded persons are placed in day care programs which are eligible for Medicaid funding rather than in work programs which are not.

Block grants, such as the Social Services Block Grant provide only limited relief to these distorting effects of Federal funding policies. The problem is that people who require social services may also require income support and/or health care and still be subject to the serious work disincentives inherent in these programs.

In consequence, many of the improvements that are needed in the service system must begin with changes in Federal policies.

Future Directions

In this section, we will identify some possible changes in the service system that would reduce the obstacles to independence that are facing youth who are transitioning from school to adult life. There are, of course, countless variations on any options that may be proposed. However, the options listed below outline the broad directions that will need to be taken in order to improve the service system for disabled Americans.

Option 1: Improve the coordination of programs so that the system of services operates in a unified and consistent way. Three ways to greatly improve program coordination are as follows:

a. Develop generally accepted and comprehensive goals for disabled persons for the entire service system. Each program would then be evaluated according to its contribution towards the achievement of the entire set of social goals. Some of the types of goals that should be included are the following: i. Promoting and maintaining the employment of disabled persons; ii. Providing adequate income support to disabled persons unable to fully support themselves; iii. Placing severely disabled persons in the least restrictive community-based residences that are consistent with their personal safety, development, and rehabilitation; iv. Encouraging disabled people, no matter how severely disabled, to participate in community activities; etc.

Two principles should guide the development of these goals: (a) They should be outcome oriented, e.g., concerned with obtaining employment, not with which agency should provide vocational services. (b) They should be described in terms of broad policy directions - specific numerical objectives are more appropriate for year to year planning.

(b) Develop a unified system for determining eligibility across programs. This does not mean these eligibility conditions should be the same for all programs, but that persons seeking services should not have to undergo multiple determinations of disability. This option would help insure that persons do not fall between the cracks, e.g., are declared too severely disabled for vocational rehabilitation, but not sufficiently disabled to qualify for SSDI/CDB or SSI.

(c) Require a unified comprehensive service plan for each client. This would not require that each agency give up its mandated service plan. Instead it would require that the various plans be consistent with each other and that each agency be aware of how it interfaces with other agencies. Some States have already instituted such a system among State and local agencies. It is important, however, that the large Federally administered income support and health care financing programs become part of this planning process.

Option 2: Establish a comprehensive information system.

The information system should be geared to collecting data to measure the degree of attainment of the social goals that may be established, to identify obstacles in the attainment of these goals, and to determine which methods of providing services appear to be most effective.

Option 3: Eliminate the emphasis on demonstrating inability to work as a condition for eligibility for income transfer and health care benefits.

Eligibility for these programs would be changed so that program applicants need only prove that they would have great difficulty in obtaining work because of their handicapping condition. Eligibility would be granted without perjorative judgments about the applicant's incapacity for substantial work. The Social Security Administration has already prepared a long list of conditions that are presumed to show inability to earn at a substantial gainful activity level in the absence of other information. Under this option, this list could continue to be used. The only difference is that a past history of substantial earnings would not necessarily disqualify a person for benefits.

Option 4: Assure that beneficiaries who return to work are always significantly better off than if they remain on the program rolls. Ways to accomplish this are:

(a) Make the 1619(a) special cash benefits program a permanent component of the SSI program.

(b) Develop a corresponding method of reducing SSDI/CDB benefits as the earnings of beneficiaries rise. This could probably not be done on the basis of decreasing benefits by $1 for every $2 of earnings as the breakeven point for some beneficiaries could be very high, in excess of $25,000 per year.

On the other hand, even a dollar for dollar decrease in benefits as earnings rise would be a great improvement over the present system. A more reasonable approach, however, would be to establish a two-phase system. In the first phase, all SSDI/CDB benefits would be reduced at the same rate as in the SSI program. Beyond that point, benefits would be reduced at a higher rate, say $3 for each $4 of earnings.

For persons receiving benefits from several income support programs, all benefits should be combined for purposes of calculating the benefit reductions that will occur as earnings rise.

(c) Make the special extended Medicaid benefits paid to SSI beneficiaries under Section 1619(b) of the Social Security Act a permanent Federal program.

(d) Grant lifetime eligibility for Medicare or Medicaid to disabled SSDI/CDB or SSI beneficiaries who return to work. However, medical benefits should be provided only to former beneficiaries who are unable to obtain private insurance coverage. Persons who receive Medicare or Medicaid benefits should not be subject to income limitations. However, they could reasonably be required to make a payment towards the costs of operating these programs in lieu of the insurance premium that they would otherwise pay, or their employers could pay into these funds the equivalent of medical costs they incur on behalf of their non-disabled employees, or both.

(e) Calculate benefit reductions in SSDI/CDB and SSI on the basis of earnings after Social Security taxes. This would have the effect of the beneficiary and the government sharing these taxes and would reduce work disincentives.

(f) Subject all SSI and SSDI/CDB (and any other income support) to income taxation. Many people receiving support from these programs have insufficient income to incur any tax liability. In the case of beneficiaries whose income is sufficient to incur income tax liability, there is little justification for exempting income from public support programs from taxation. However, if benefits are to be taxed, equity would require that income used to pay Social Security taxes be exempt from taxation.

(g) Establish modest earnings disregards for child care and normal work expenses.

Option 5: Award lifetime eligibility for SSDI/CDB, SSI, Medicare, and Medicaid to people who establish eligibility for these programs unless there is significant medical improvement. Lifetime eligibility for SSDI/CDB is feasible only if a system is implemented to reduce benefits as earnings rise.

This will remove the disincentive for beneficiaries to accept work that is part-time, temporary, or insecure. It would also resolve the current inequity in the Section 1619(a) and 1619(b) programs where beneficiaries lose all entitlement to benefits if they temporarily lose their program connection. There are, of course, other ways to resolve this latter problem, e.g., not losing eligibility unless the program connection was lost for a given number of consecutive months, probably 4 to 6 months.

We already noted that lifetime entitlement to Medicaid and Medicare is needed for some beneficiaries as a way of assuring that they are not made worse off as a consequence of accepting substantial employment.

Option 6: Make disabled persons eligible for SSI or SSDI/CDB if their income falls below the breakeven points for these programs. Similarly, make disabled persons eligible for Medicaid or Medicare if they have a disability that makes it impossible to secure private coverage.

This option is necessary to remove the incentive to establish eligibility for these programs before seeking substantial work (and probably developing negative attitudes toward work).

Option 7: Develop methods for supporting community-based residential care for severely disabled persons in settings that are not medical in orientation or that require 24-hour-a-day oversight.

A substantial part of the cost of this option would come from redirecting current Medicaid dollars supporting care in nursing homes and ICFs/MR into community based housing. There have been numerous proposals for doing so. Some of these proposals were directed at the ICF/MR program and envision a phasedown of institutions for persons who are mentally retarded. Other proposals have been more broadly conceived and would encompass aged, physically disabled, and mentally ill persons as well as persons who are mentally retarded, usually by developing a block grant for long-term care. One proposal would make the Home and Community Based Services Waivers program an optional program to States. To be fully effective, however, the requirement that limits the number of persons that can be served to the number that can be placed in institutional care would need to be relaxed.

Option 8: Develop methods of providing Federal funds for transitional and supported work activities for severely disabled persons.

In part, this option would be financed by redirecting existing Federal and State resources used for day activity care and sheltered workshops to transitional and supported work activities. It is not clear, however, as to the extent to which these activities should be undertaken by existing vocational rehabilitation programs, and to what extent they should be undertaken by agencies such as mental health agencies, MR/DD agencies, and other agencies with a long-term relationship with severely disabled persons. A number of States are investigating alternative methods of providing supported work and transitional work opportunities for severely disabled people and the advantages of the alternative approaches should become clearer in the near future.

Option 9: Reduce the severe restriction on the level of countable resources allowed to SSI beneficiaries in order to encourage savings.

At present, it is anticipated that the amount of countable resources permitted will rise annually in $100 increments for individuals and $150 for couples until 1989 when the limits on countable income will rise to $2,000 for an individual and $3,000 for a couple. However, this relatively modest rise is unlikely to be sufficient. One alternative would be to impute a return, say 10 percent, to the countable resources over the exempted amount and deduct this imputed return from SSI benefits. For example, if a beneficiary had $6,000 in countable resources over the exempted amount, then assuming a 10 percent annual rate of return, the imputed monthly income would be $50 which would then be the amount deducted from the SSI payment.

Implementation

The above options do not represent a major departure from current policy. Many of the options had their roots in the Social Security Disability Amendments of 1980, e.g., the suggestions that Sections 1619(a) and 1619(b) be made permanent and a similar program instituted for SSDI/CDB. Similarly, granting lifetime eligibility for income transfer and health care programs is basically an extension of the 15 month re-entitlement period after the trial work period and the 36 months of extended eligibility for Medicare coverage. Moreover, most of the options for the income support and health care financing programs already exist in the SSI program for persons who are blind. Persons who are blind are not subject to an SGA test of earnings capacity at application for SSI benefits, only to an asset test. Once they are declared eligible, they are entitled to benefits for the remainder of their lives.

Nor are these options necessarily costly. A great deal could be accomplished by redirecting funds currently used for institutional care and day care into funding community residences, and supported and transitional employment activities. Moreover, although some of the options may increase the number of persons entitled to SSDI/CDB, SSI, Medicare, or Medicaid, the intent of these options is to **increase the incentive to work** so that some persons currently drawing benefits should reduce the amount of benefits they receive and perhaps cease receiving benefits altogether. Nor must we forget that beneficiaries who return to work will pay (with the employer's contribution) almost 14 percent of their income into the Social Security and Medicare trust funds. **The net effect of the conflicting influences could well be to lower costs.**

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Excerpts of Reviews and Comments

The following are excerpts of reviews, comments, and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as it relates to the content of Chapter Three by Ronald W. Conley.

The enormous number of cases he references as being litigated in workers' compensation is probably the result of a number of elements. Certainly it is contributed to by misassessment of cases, but it is probably as much contributed to by a "suit happy" social upbringing as well as the erosion in the state judicial systems of issues related to the workers' compensation claims.

We should consider adding to the Medicare burden continuous coverage as a secondary carrier for disabled persons. Suggest that disabled persons pay a $10 per month fee to the Medicare program for purposes of catastrophic coverage taking over after current employer's coverage hits $30,000 in benefits in a secondary position to the employer coverage. It would help employers consider hiring increasing numbers of handicapped employees if they could be assured that they wouldn't be alone in footing the bill for catastrophic coverage. The disabled person who has a job should help in the providing of that coverage by paying a minimal fee. There would also have to be sufficient provision in such coverage indicating the disabled person's financial liability for that $10 fee per month so that if he fails to continue that payment the burden does not fall back on the unsuspecting employer.

-- ELIZABETH DEMPSEY

My first response to reading this exceptionally informative paper was to quiz myself on the first dozen pages: What did **I**, as a professional in this business for the past 20 years **really** know about the intricacies of these programs and the complexity of the decisions that must be made regarding the pros and cons of entering the labor market. My answer was: beyond the fact that they exist - not much.

The complexity of the patchwork of eligibility and entitlement programs that currently exists is overwhelming for the professional - how much more so must it be for the consumer and his/her caregiver's (parents or guardians).

I was struck by the need within our disability system to quantify the unquantifiable through ratios, formulas and paybacks. And yet, the unpredictability of three variables: 1) medical improvement/regression, 2) labor market forces and 3) system/program financing and continuance make it hardly worth losing the certain security of benefits for the uncertainty of a job. There is little we can do about the first two variables but much we can do about the third, as Conley notes in the recommendations he makes in the conclusion of his paper.

We must work on removing the **professional's** disincentives to working with severely disabled clients. Long term or life long vocational support services are virtually non-existant. As Conley notes, the present vocational rehabilitation system is **not** designed to serve this function.

Rehabilitation counselors are rewarded for serving many short term clients. There are enough severely disabled short term clients around without over-extending themselves with the long-term ones. Unless employment is guaranteed as a right (e.g., public sector employment) and rehabilitation agencies participate in some meaningful way in supporting employment over the disabled person's lifespan, the appeal of work disincentives will remain.

Currently, supported work projects are subject to the vagaries of funding priorities. Recently, ten state vocational rehabilitation agencies were awarded funds (competitively) to establish supported work programs. The concern is whether these programs will elicit state funding if and when the federal trough runs dry.

Finally, to return to a point I made earlier, the educated professional is sorely needed so that they may assist consumers and parents in the advocacy process. Special education personnel know precious little about rehabilitation services and other programs which may assist in the transition process. Conversely, rehab folks often dismiss the input of special education types as unrealistic and irrelevant. Frequently, turf and boundary issues prevent cooperation as with the rejected SSI applicant who is nonetheless not eligible for vocational rehabilitation services.

The coordination of services is also limited in the transition process to the intrinsic differences between an entitlement system (special education) and an eligibility system (vocational rehabilitation).

Conley makes some very realistic and achievable recommendations for providing an "umbrella" system which would unite diverse programs and reduce disincentives to work. I would hope the assembled group at the seminar could agree on strategies for putting these recommendations into disability legislation.

-- MARITA M. DANEK

The removal of work disincentives is a major obstacle that must eventually be addressed at the national level among heads of the various departments of government who administer the service programs involved. While some gains have been made in recognition of this vast problem (Section 1619 of the Social Security Act; calls for the establishment of consumer-advocate and service provider task forces and work groups to study the issue of disincentives and make recommendations), we need more than a demonstration effort. It is acknowledged that an individual will not willingly "give up" and assured income or benefit to confront a risk situation. Presently, the **loss of income maintenance** and **medical assistance support** are the prevalent factors impacting on the parental decision to attempt movement of disabled youth from a "protective" environment to the uncertainty of independent living and/or employment. In addition, parents and consumer advocates are concerned with the **total life functioning aspects** for disabled youth. As an example, what are the total support mechanisms that will be available to the disabled person when parental support is no longer available due to illness, death or other circumstances. The **safety net** that exist through income/health maintenance and within institutions, sheltered workshops, etc., will in many cases preclude any mass exodus from these environments.

The work disincentive issue points out an even greater need for coordination among the Federal and State programs involved in social and human services. The fact that each have traditionally operated in isolation from the other has been cause, to some extent, by the system in which laws and regulations are enacted without regard to programmatic cross-over effects or benefits. The Congress has only recently begun to recognize the magnitude of the **disincentive issue.** Consumer interest and influence will probably be the most effective vehicle for bringing about change.

The issue of utmost importance is whether or not a movement to change regulatory impediments to employment can be realized. This will of course require public influence at all levels. A major concern would be whether consumer involvement could occur at the degree and level needed to enact change. The complexities surrounding the Social Security programs and other locally administered programs such as medicaid, are enormous. Revisions to present Federal laws and regulations will require considerable focus on the extenuating disability-related circumstances that might occur during the life span of a disabled person. The approach to locally administered income/health maintenance programs would present an even more diverse and complex issue. In the meantime, where do we start?

Many of the non-monetary disincentives to employment need also to be addressed. A major prohibitive factor confronting both physically and mentally disabled persons concerns **the inaccessibility of transportation, housing and lack of adequate mobility orientation,** that is, getting to and from the residence to the job site.

-- MIRIAM E. WALKER

Ronald Conley's paper on public policies **obstructing transition** is an excellent illustration of the morass that a disabled person has to wade through either in acquiring support services through various beneficiary or insurance programs or in sustaining one's self within competitive employment. Is it any wonder that our society has seemingly taken a legalistic bend as we've increased the complexity of our various disability programs.

The key to Conley's entire paper is the conflict between the **least restrictive environment** as a program goal and the belief that disabled persons can be evaluated and neatly divided into those that are capable of substantial gainful activity (SGA) and **those who are not.** As pointed out in his paper, many have recognized the inconsistencies between these two considerations and have attempted to apply corrective measures. Unfortunately, these corrective actions in most cases have only increased the complexity of an already difficult topic.

If we were to apply an analogy to this issue, it could be suggested that we are seeking to modify a Model T Ford in such a way that it would address the transportation needs of today's society. We recognize that this vehicle will need to be modified in such a way that it will accommodate a family while it, at the same time, obtains 35 miles per gallon while going 65 miles per hour down the highway (with a passive radar detector in place). The SSDI (Social Security Disability Insurance) and the SSI (Supplemental Security Income) programs represent the basic frame of our special vehicle, and the benefit derived from these programs is the fuel that moves our vehicle along. If we were to think that the ultimate destination of this vehicle would be competitive work for its passengers, we may identify that there are some internal inconsistencies that causes this machine to run rough and to occasionally stall.

A number of alleged mechanics felt that the vehcile could be modified to improve its efficiency. The Social Security Disability Amendments of 1980, specifically Sections 1619A and 1619B, represents a turbo-charger on the Model T's small four cylinder engine. Other mechanics restricted the speed of this engine by attaching a governor with the 1984 Amendments to the Social Security Act. Unfortunately, the jerking about of the vehicle confuses the passengers of the vehicle and causes the driver to become undecided as to whether to step on the accelerator or to slam on the brake. The service stations along the way representing ICF/MR programs and sheltered workshops are inviting alternatives to the perilous journey on life's super highway.

Conley's future directions suggests that if we were to continue with our analogy that we should park our modified Model T and design a totally new vehicle, one which would be specifically designed to allow severely disabled persons to keep up with traffic on that previously referred to super highway and, in some cases, even move into the passing lane. Conley's first option suggests that our vehicle's design should come from designers who have **coordinated their efforts.** They should start with a **common goal** and a similar understanding as to how that **goal can be achieved.** Option two suggests that a comprehensive information system be a part of the car's internal system. This information system keeps the passengers fully informed as to the vehicle's status and, by satellite, reports back to the manufacturers so that the design can be refined as the highway conditions change. Option three throws the Model T's operating manual away. This manual specified that the vehicle must be ready for the junk yard before it can be fixed. Option four is a warranty for the driver and its passengers insuring them that they are better off in the vehicle on the way to its goal in contrast to being parked in a garage. Options five and six insures those that are severly disabled will be able to have the car appropriately serviced in such a manner that they will be able to make continued progress toward their goal. Option seven remodels those service stations along the way so that only those services that are essential are performed so that the vehicle may proceed on its way in the most expeditious manner possible. Option eight insures that those new service stations are kept up-to-date and in tune with the needs of this new vehicle and its passengers. Option nine enables the passengers of the vehicle to carry much more baggage so that they can be more effective once they arrive at their destination.

In effect, the nation's disability system needs its own Lee Iacocca and the equivalent of a Chrysler K car. Like Chrysler, this entire effort will require a **federal bailout,** so this new vehicle can be designed to prevent not only the bankruptcy of the system, but also the **loss of the human potential** of the hundreds of thousands of persons with severe disabilities.

-- MARVIN L. TOOMAN

The monograph by Conley brings to our attention the numerous federal programs that have an impact on the lives of persons with disabilities. It is shocking to recognize the myriad of programs we have created to assist people, while at the same time we have **created barriers, disincentives,** and **conflicting rules** in an attempt to regulate these programs. The main focus of my professional career has been providing direct job placement services to persons with disabilities, and therefore dealing with disincentives is a daily occurrence in our offices. The **Certified Rehabilitation Counselor** who works in the **Projects With Industry** program must be able to clearly present the assets and liabilities of full-time competitive employment versus disability insurance or government subsidy. The vast majority of people we see would prefer to work rather than accept public assistance or disability benefits.

The Conley monograph also creates the image of Public Aid and Social Security offices with lines of people applying for assistance, mountains of forms to be completed and the bureaucracy at work. An important aspect of a rehabilitation counselor's training is to treat every person who comes to us for assistance with **dignity, respect** and **personal attention.** We must continually remind ourselves how we would like to be treated when dealing with a large organization.

Conley also reminds us of the importance of **follow-up** and **follow-along services** for those individuals who are in the transitional phase and those individuals who have made the transition and are employed. There needs to be an increase in the number of programs which have the professional staff to provide follow-up services.

It seems logical to **expect** that people who have had problems entering the labor market will continue to have problems adjusting to the world of work once they find employment. Although some programs may appear costly by providing personal attention to the individual with a disability, I believe the investment is sound when we consider the pride and dignity of **competitive employment** and **independence.**

-- ALLEN R. SEARLES

In presenting his argument, Conley has developed a chronology of service available to persons with disability in the United States that includes: (a) social support, (b) health care, (c) employment, (d) housing, (e) education, (f) social service; most of which is funded and regulated by the federal government.

He has throughout most of the paper developed a strong case outlining the **negative impact** upon work incentives that administration of the various income supports and health care financing programs create. To assess the disability policy in the United States Conley maintains that the combined interacting effects of these programs on persons with disabilities is relevant. The interaction effects of these programs exacerbate the work disincentive problems instead of assisting or encouraging work incentives to persons with disabilities.

Over the past 25 years there has been revolutionary changes in the social goals for severely handicap-ped Americans; however, achieving these goals is dependent upon availability and **appropriateness of services** and supports from a system that presently creates obstacles.

Conley provided a detailed analysis of the present income support and health care financing programs with descriptions and examples of how the interaction of these programs often combine to create major disincentives to work. Individuals with disabilities often choose and are encouraged by the system and those professionals with whom they relate to opt in favor of benefit retention instead of seeking work. Security of income support creates strong work disincentives.

Although Congress has in recent years enacted Social Security legislation on a time-limited demonstration basis which would have an effect on reducing work disincentives, Conley directs our attention to the need for **more sweeping policy changes.**

Moving to employment programs Conley raises some serious and counter productive policies and procedures that mitigate against effective long-term vocational services including the state vocational rehabilitation agency use of numbers of successful closures as **a measure of counselor success.** This policy fosters the practice of avoiding the difficult case thus a bias for case-closure expediency.

Also the use of **adult day care** for the mentally retarded/developmentally disabled person instead of vocationally directed programs in order to receive Medicaid funding is noted and this is an economic expediency. A third person for limited services to move **severely disabled adults** into integrated work settings is the relatively new initiative toward **supported employment.** Financial incentives for states to provide these services is urgently needed.

Conley raised nine options which outline broad directions that need to be taken in order to improve the services system for Americans who are disabled. Each of their options should be explored for feasibility and practicality. Should other options be considered? Can they be prioritized?

A set of strategies will obviously be required to actualize these priorities. The implications for activating and emplementing these options seem challenging; however, Conley's arguments for a systems change is loud and clear.

-- CARL V. PULEO

Conley has provided a succinct account of the various public policies which provide support and services to disabled persons. The paper has identified aspects of public policy which appear to be obstructions to public policy.

In studying the paper I became more aware of the "risk" individuals and parents might be taking by **chancing employment.** The fact that public support could be lost, sometimes permanently, should caution transition programs to proceed cautiously. This paper is must reading for individuals operating transitional employment programs.

This paper could be the basis for a practical Q & A publiction to assist parents , professionals, and disabled individuals to understand the current policies. Another related publication could emphasize how emerging transitional employment programs can go to the limit without jeopardizing client eligibility for basic support.

The Future Directions section is well thought out and the options appear as realistic recommendations for policy alteration to reduce disincentives. The time has come for a broad-based discussion of the options by policy makers.

-- WILLIAM HALLORAN

This excellent and thorough overview of the disincentives to independence and employment inherent in various State-Federal services - Income Support, Health Care, and Employment Programs -- provides specific options for remedying these problems which are not necessarily new, not major departures from current policy, and not costly. A major task ahead of us in rehabilitation and through the Associations with which we affiliate is that of **educating legislators and the general public** about the merits of the options as outlined. This effort is but one piece of a larger education effort we need to target toward enhancing public awareness of and acceptance of individuals with disability. Lack of such public awareness and acceptance is, I believe, the major reason for inadequate funding in support of many social programs in this country, such as the State Federal Vocational Rehabilitation Program which is currently **funded nationally at such a minimal level that one (1) in twenty (20) individuals needing these services can access them.**

-- AMOS SALES

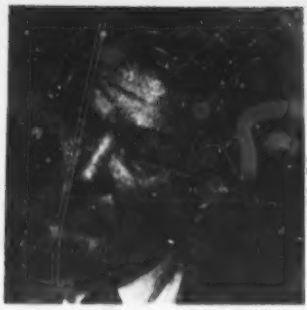
MARY'S FRIENDS: Edna Adler, left, from RSA and a Scholar at the 6th Seminar visits with Boyce Williams, now of Gallaudet College. Williams worked for Mary Switzer at RSA at one time.

Seminar Scenes

PRESIDENT LEE: Gallaudet President Jerry Lee attended parts of the Seminar, gave a welcoming speech and hosted the reception at his home.

PAT AND GARY: Pat Morrissey (l), Deputy Commissioner of RSA and Gary Austin enjoy the Reception.

RECEPTION: Scholar Marita Danek visits with Coordinator Leonard Perlman



Switzer Scholar Hanks

Chapter Four

Costs and Other Economic Considerations in Transition Programming

by Dale Hanks

The National Center for Education Statistics reports that in 1983 there were 4,255,000 public elementary and secondary students in educational programs for the handicapped., The U.S. Office of Special Education and Rehabilitative Services (OSERS) estimates that 250,000 to 300,000 of these students leave special education each year. Most of these youth need additional help beyond school in making the transition to the world of work. Moreover, many other students with disabilities graduate or leave from the regular curriculum but, nonetheless, require rehabilitation services to obtain employment.

During the past decade, economists and other social researchers have participated in a number of experimental programs to find better ways and means for assisting unemployed youth and adults with disabilities to find and hold jobs in the open community. In the pages that follow I investigate some of these newer programs to examine their costs and other economic aspects. I also explore some of the difficulties in evaluating the effectiveness and efficiency of transition programs, and assessing their costs and benefits. Finally, I consider some of the policy implications suggested by these attempts to estimate the costs and understand other economic factors of transition programs.

I believe that economists and others engaged in social research have a great deal to offer in improving our programs and policies aimed at helping people with disabilities to work at real jobs in the open community. Perhaps the principal thing they offer is the ability to make the rest of us uncomfortable. They speak of alternatives to the same old activities we are used to. They ask troublesome questions about the benefits and costs of our programs. Even though we are surely content doing God's work, if resources are limited, they want to know who gets left out.

Since demands for rehabilitation resources exceed the supplies we may conclude that efficiency in the use of those resources should be an important consideration in the way they are allocated. The wide range of disability programs initiated following 1973, and the duplication and overlap of programs servings persons with disabilities add a sense of urgency to finding out where the money goes and what good it does. Which program or combination of programs is most effective in helping potential workers with disabilities to make the transition from unemployment or underemployment to the competitive market can only be determined through research, demonstration, and experimentation. And unless the results of these efforts can be translated for improved decision making, the status quo will continue to dominate our programs and policies.

Sooner or later, cost considerations and other numbers enter the deliberations of decision makers as resources are allocated for the public good. Moral and ethical arguments being equal, the extent to which program people can provide policy makers with adequate information about the benefits and costs of transition strategies will determine, in large measure, their ability to influence resource allocation decisions.

Evaluating Transition Programs

OSERS has defined transition programming as an outcome oriented process encompassing a broad array of services and experiences that lead to employment. Transition is a period that includes high schools, the point of graduation, additional post secondary education on adult services, and the initial years in employment.

Evaluation processes in transition programs, like other social and rehabilitation efforts, usually revolve around the analysis of data to measure their **efficiency** and **effectiveness.** Efficiency is defined as the extent to which program administrators deliver maximum services for the resources spent. Effectiveness, on the other hand, is understood to mean the extent to which a program achieves the objectives for which it was designed.

Efficiency reflects the quality of program management, while effectiveness reflects the quality of the program itself and whether or not it is conceptually sound. Simply put, effectiveness and efficiency reflect different qualities about different things and require different kinds of judgments. It is not always clear why a program works or does not work. Both failures and successes can be because of the people running the program or the very concept with which the program is built.

Most attempts to measure efficiency and effectiveness in transition programs include the following approaches:

1. **Dollar cost per client.** For example, "it cost $5,000 to successfully train and place one program participant."
2. **Dollar cost per unit of service.** For example, "it costs $8 for one training session for one program participant."
3. **Units of service per client.** That is, "one participant requires 27 training sessions."
4. **Objectives achieved in units of service.** For example, "of 45 parent training sessions planned for this year 30 or 66 percent were held."
5. **Objectives achieved in clients served.** Or, "of 100 planned client placements in jobs this year, 80 or 66 percent were placed."
6. **Benefit-cost analysis.** For example, "the net present value (benefits, less costs) for society is $2,271, and the benefit-cost ratio for program participants is 1.82." (We will consider this in detail momentarily.)

The first three measurement approaches above relate costs to services for clients, and are efficiency measures. Four and five compare intended performance with actual performance and may imply either measurements of efficiency or effectiveness. Number six (benefit-cost analysis) compares social costs to benefits and is an effectiveness measure which also attempts to support judgments concerning the economic efficiency of a program.

Benefit-Cost Analysis

Benefit-cost analysis seeks to answer two kinds of questions: (a) is the program efficient? and (b) is it equitable? From the broader perspective of benefit-cost analysis, efficiency measures try to get at a program's effect on the total value of goods and services that are available to society. The question is whether or not the value of those goods and services is increased by a particular program. On the other hand, equity has to do with the distribution of goods and services among various groups in society. The principal equity issues relate to how a program affects that distribution, and who benefits and who pays.

In its purest form, benefit-cost analysis seeks to apportion a dollar value to everything and, by discounting, to determine a rate of return or net present value for alternative courses of action. When benefit and cost components of a benefit-cost analysis are compared the comparison has to be at a given-point in time. Since both benefits and costs usually accrue over a period of years, they must be discounted to account for the time factor, There are three common methods of comparing benefits with costs: (a) present value of net benefits, (b) rate of return, and (c) benefit-cost ratio.

Present value of net benefits. The present value of net benefits is calculated by discounting the stream of future benefits back to the present, which is usually defined as the time a person or group finishes a program. The accummulated costs are then subtracted from the total of benefits calculated at the same point in time. This tells us the absolute size of the gains resulting from the program.

A positive net present value indicates that resources are being used efficiently. A negative net present value suggests that the program's resources could be used more efficiently elsewhere -- or that its current level of activity needs adjusting. The appropriate discount rate to use in evaluating social programs is still open for debate. Most studies use rates from 3 percent to 10 percent. Schalock (1985) suggests that one procedure is to assume a middle value of 5 percent and then test the sensitivity of the findings to the assumption by recomputing the discounted values (present values) using 3 percent and 10 percent discount rates. By comparison, the Office of Management and Budget uses a 10 percent rate for evaluating government investments.

Monroe Berkowitz (1982) has used a simple example to explain the concept of discount rates vis-a-vis investment in human capital. According to Berkowitz,

> *Rehabilitation expenditures go toward improving the productivity of human being and can therefore be thought of as investments in human capital. These expenditures represent investments since the costs that are incurred today yield a stream of benefits in the future. If we wish to compare the present costs with future benefits, we need some way of expressing the costs and benefits in the same way and of considering their value in the present. At base, we need to answer the question, what would it cost me to buy the stream of benefits if I made my purchase today. If, for example, I put $100 in the bank and receive 5 percent interest on my money, I can then receive $5 per year forever. Therefore, it has cost $100 to purchase an income stream of $5 per year. This notion is often put into the jargon of finance by calling $100 the "present value" of $5 per year. The 5 percent interest rate gets translated into a rate of "discount." Putting these ideas together, we can then make the following statement. The present value of $5 per year discounted at a rate of 5 percent is $100. The statement enabled us to better understand benefits and to make more accurate comparisons with costs.*
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> *In the rehabilitation program, the benefits do not take form of an infinite stream. People die; people change their productivity and that in turn influences their wages; people get sick; people retire; and people lose their jobs. Rehabilitation, in other words, is not a magical intervention that produces a permanent cure. Rehabilitants live in the real work and face all the real world's problems. In addition, calculations of present values are strongly influenced by the discount rate that is chosen. The higher the discount rate, the lower the present value of a particular income stream. If interest rates are higher, it costs me less to buy a particular income stream.*

Rate of return. The rate of return is calculated by finding the interest rate which will equalize the value of costs and benefits. This indicates the rate of interest the "investment" in the program is earning.

Benefit-cost ratio. The benefit-cost ratio is calculated by dividing the present value of benefits by the present value of costs. This ratio shows the size of the gain relative to the size of the investment. The benefit-cost ratio differs from the present value of net benefits because it tells us the relative size of the gain instead of the absolute size of the gain. Benefit-cost ratios focus attention on gain per dollar spent, and is an appealing concept to program administrators operating under tight budget constraints.

Components. Policy analysts are generally agreed that the benefits and costs of social programs can be appropriately viewed from the standpoint of society, the individual, and the taxpayer or government. The benefits and costs are not the same for each, nor are the objectives and relative importance the same for each actor in the scene. Essentially, society would benefit from a transition program to the extent that total income is increased without regard to the distribution of the income or what happens to taxes. Program participants, however, who pay the resulting taxes do not benefit directly from them, so they must be deducted from increased earning when individual benefits are calculated. On the other hand, the government would gain the increases in tax revenues generated by increased earnings, but it would not gain the full benefit from increased earnings as would the individual and society at large.

Bruce Davie (Barsby, 1972) has outlined the various components of benefit-cost analysis and how they may be combined to enable policy makers to make better informed decisions about resource allocations. In calculating the benefits and costs of a given activity, Davie suggests a general structure which includes perspectives from society, the individual, and the government. In calculating the benefits of a given activity, Davie breaks the components down this way:

- *Society benefits from increased earnings of program participants; from a reduction in administrative expenses of transfer payment program; and from reduced costs associated from idleness which leads to poor citizenship.*
- *The individual benefits directly from an increase in earnings and additional fringe benefits.*
- *The government benefits from an increase in tax revenue together with a decrease in such expenses as welfare programs and crime control.*

In calculating the costs of a given activity, Davie offers the following concept:

- *Society is faced with "opportunity costs" defined as a benefit lost which might otherwise have been attained by allocating resources for other programs or purposes; operating costs of the training agency; capital outlays of the training agency; and reductions in income of workers displaced by program participants.*
- *The individual also would experience "opportunity costs" of wages foregone while in training; loss of transfer payments from public programs; and extra costs related to program participation such as tuition and books.*
- *Government costs would include costs of instruction and supplies; capital outlays; additional administrative costs required by the activity; and additional subsidies paid during training.*

Alice Rivlin (1971) has discussed some of the weaknesses of benefit-cost analysis and concludes that once the analysis leaves the fairly firm ground of income we enter a kind of never-never land where values must be set on self-reliance, freedom from fear, pleasures of clean air, and so forth. She believes that result may not be worth the effort.

Rivlin suggests that policy analysts would be wasting time and effort by giving high priority to making dollar estimates of the benefits of social action programs. Politicians and other decision makers have strong intuitive ideas about the relative importance of health, education, and social well-being that are not likely to be shaken by benefit-cost estimates. However, benefit-cost analysis is a way of showing politicians and their constituents what is really happening which poses the question -- is this really what you meant to do?

Rivlin believes that benefit-cost analysis can be most useful when applied to programs that are designed to increase future income. The justification for benefit-cost analysis is especially valid when the decision involves alternative ways of increasing the income of the same people. Benefit-cost analysis contributes to choices between income maintenance and various types of human investment programs as routes out of poverty for the same people. We may consider, for example, alternative policies by comparing extended employment in workshops with on-the-job training or other forms of transitioning techniques leading to employment.

The office of Technology Assessment (OTA) of the U.S. Congress (1983) reports that interest in cost-benefit analysis (or its inverse, benefit-cost analysis) is growing. OTA finds that although cost-benefit analysis has been conducted frequently in the disability area, little evidence exists of its use in affecting policy. OTA explains that the reasons for this lack of policy impact are numerous and logical. Cost-benefit analysis suffers from a number of serious weaknesses, both of immaturity and of an inherent methodoligical nature.

OTA points out, however, that some deficiencies of cost-benefit analysis related to the state-of-the-art in the disability areas may diminish as techniques improve. Moreover, as policy analysis and decision makers gain more experience in using these kinds of analyses, their usefulness may increase. In a later section we will examine some of the newer techniques in benefit-cost analysis that have been applied to transition programs.

Some Difficulties in Estimating Costs

There are a multitude of terms that distinguish one kind of cost from another. For example, in government programs we find fixed costs, variable costs, incremental costs, sunk costs, recurring costs, nonrecurring costs, internal costs, external costs, direct costs, indirect costs, operating costs, maintenance costs, labor costs, and so on ad infinitum.

In public policy analysis, decisions are not free of costs whether or not they lead to the expenditure of money. Costs are much more than the expenditure of funds, or the consumption of resources, or the dissipation of time. Every public program generates costs. Sometimes these costs may be outputs that follow as a result of a policy decision as well as inputs that are necessary to implement it. For example, when the government spends money to build roads for ease in travel, it must also spend money to patrol the roads and prosecute speeders.

Moreover, the word cost may be used by different people at different times and in different contexts so as to make possible a number of different interpretations. In some state vocational rehabilitation agencies, for example, it is a practice to refer to individual client plans in which no direct case service expenditures are made as "no cost" plans. This is a very restricted view of the costs of rehabilitation.

In matters of public policy, costs are the negative impacts associated with a decision, and the benefits are the positive values. Decision makers, of course, seek to minimize costs and maximize benefits. The tricky part about this is that one person's cost may be a benefit to another. It all depends on their objectives.

Bickner (1971) presents an interesting situation to illustrate the various ways in which the word "cost" might be used. He suggests that we might consider the "cost" of stopping by the neighborhood bar on the way home from work tomorrow. This might "cost" you (a) an expenditure of several dollars, (b) a chance to watch your favorite newscast and stock market report, and (c) a hangover. What would be the "cost" of stopping by the bar? Would there be "costs" incurred by others such as the bartender -- or customers -- or your spouse?

Clearly, if we define "cost" only in terms of dollars then we will not be able to make rational decisions simply by comparing cost with benefits in such a restricted sense. Decision makers need to have a clear notion about the meaning of "cost" because determining the costs of most government programs is much more complex than figuring out the cost of stopping by your friendly neighborhood tavern.

Bickner points out that to be comprehensive in estimating costs, our categories cannot be limited to expenditures of money or to budgeting commitments. It may sometimes happen that our only concern is with dollar expenditures. In such cases, we should use the term "dollar expenditures," not "total costs." To emphasize the need, and also the difficulty in being comprehensive, it is helpful to distinguish costs according to their measurability. For example:

1. *Dollar expenditures.*
2. *Other costs that can be evaluated in dollars.*
3. *Other costs that can be quantified.*
4. *Other, nonquantifiable costs.*

Dollar expenditures are largely self-explanatory. Other costs that can be evaluated in dollars include the consumption of resources which might not affect dollar expenditures immediately or directly, but which can be conventiently evaluated in dollars. An example would be the consumption of paper stock that would require replenishing in the future. The third category might include time lost due to unforseeable delays in scheduling and programming. In the fourth category of costs we would include such things as using some of the limited reservoir of public good will for certain program aspects, or burdening staff morale.

Opportunity costs. Economists view an economic cost as a benefit lost. For example, if we choose to apply our education and rehabilitation resources to expand an existing program, then these resources are obviously not available to develop some other program which might be superior. An estimate of the cost of such a choice is an estimate of the benefit that could otherwise have been attained. These costs are often referred to as "opportunity costs" because it is in the foregone opportunities that other meanings of cost are found. This is the reason you might sometimes hesitate to spend a dollar, because you would forego the opportunity to buy something else.

Within the concept of opportunity costs as being benefits lost, we can conclude that costs and benefits have the same dimensions. Without this logic, it would be impossible to compare costs and benefits. That is, unless the two concepts of costs and benefits have the same dimensions then it would not mean much to say that the costs of a certain program exceed its benefits, or vice versa. Costs and benefits are opposite sides of the same coin and those who make public policy have to consider their relationships to each other.

Joint costs. Another problem in estimating program costs concerns joint costs. The problem of joint costs emerges when a given expenditure, such as facility maintenance or administrative services, serves a number of program activities either in sequence or simultaneously. The problem is in determining what portions of these costs to allocate to the various activities. Often these costs are allocated on the basis of the relative sizes of the activities they serve. There is probably no "right" way to do this, but in any case the question of joint costs should not be ignored in estimating costs of a particular program.

Other problems in estimating costs. One of the most common problems encountered in estimating costs of governmental programs is the lack of good accounting data. As a result of this, policy analysts may often havze to depend on educated guess to determine program costs.

Lack of good accounting data introduces a more subtle problem -- the use of average rather than marginal costs in analyzing program performance. Average costs can be calculated with less detailed data than marginal costs. However, average costs provide more of a historical perspective to see where we have been, rather than to decide future directions. Average costs are not very useful in indicating to us whether we should expand, maintain, or decrease the level of a program, or its component parts. To get this information we need what economists refer to as marginal costs. Costs at the margin tell us how much the total costs of an activity will change when we change the level of activity by some small amount. That is, if we add one more counseling session, for example in the transition process this will add a marginal increment to the service costs. Also, it should add some marginal improvement in the success rate of transitioning. Since there are many such ways to increase the effectiveness of a program, we will need to estimate the marginal costs of competing alternatives to allocate our resources to the best one.

Barsby (1972) reminds us that benefit-cost studies that rely on average cost calculations to make suggestions concerning the level of some program (i.e., should the program be expanded or contracted) have this serious often unrecognized deficiency. As Monroe Berkowitz (1983) has put it,

> *Vocational rehabilitation programs come in may shapes and sizes. Impressive displays of the programs' average effectiveness do not address the real issue. To show that the average cost-benefit ratio is high says nothing about the cost-benefit ratio of rehabilitating a particular severely disabled or elderly client. If we can return from the real to the ideal, we might say that we are most interested in the return on what might be called the discretionary dollar -- not the first dollar or an average of all the dollars but the very last or the marginal dollar spent. There, at the point that economists call the margin, is where decisions need to be made.*
>
> *Not only do programs come in different sizes, they also*

provide a great number of different services. Funds are spent for counseling, guidance, training, administration and a whole host of other activities. To divide all benefits by all cost and arrive at an average benefit-cost ratio misses a lot of the important policy decisions and details. Some costs may yield greater benefits than others and rehabilitation agencies may take a vital interest in these matters. All in all, therefore, we care more for the extra or for the marginal benefits, than we do for average benefits -- the benefits at the point of decision rather than an average of the benefit at all the points.

Ultimately, we want to determine the surplus of benefits over costs. Economists can demonstrate that this surplus is greatest when the benefits and costs are just equal at the margin. In order to grasp this point, one might think of a series of surpluses which occur when the program reaches a certain size or accepts certain clients. As long as benefits exceed costs at the margin, the size of the total surplus grows larger and larger. As the program grows and accepts more clients, the surplus may grow at a progressively slower rate. Nonetheless, it continues to grow. At some point it reaches its maximum size and this point is where the benefits exceed the costs by the smallest possible amount. After that point, the total surplus begins to fall. If funds for rehabilitation were unlimited, the wisest policy would be to expand the program until these total benefits were at a maximum, that is, just at the point when the benefit from the last or marginal expenditure exceeds the cost from that expenditure by the smallest possible amount.

Forgetten costs. Jean Simkins (1979) has noted that even when a clear cost-benefit advantage cannot readily be demonstrated, the costs of disability accrue regardless of whether or not rehabilitation services are available. Further, she reminds us that a good deal of the costs with which cost-benefit studies necessarily concern themselves such as medical and custodial costs will be incurred in some form regardless of conclusions about cost-benefit ratios. Therefore, a real net benefit is the difference between not doing all that could be done in the way of rehabilitation and the cost of what is done.

Simkins has invented the following diagram which expresses her idea schematically:

x y

costs incurred
either way
(essential care
accommodation,
daily living

A^s "negative" cost i.e., the cost of what is not done
B^s costs of what is done
x^s the costs of avoidable extra dependence, e.g. more attendants or more active nursing needed as a result of lack of mobility aids; aid in kind because of nil or abnormally low earnings; institutional care because suitable housing not made available; costs in respect of dependents
y^s the cost of what is done to aid independence: e.g., the cost of self-care training; aids to mobility (physical and financial aids); the provision of suitable housing; help to obtain employment including extra costs for basic education, training and job procurement

Net benefits arises whenever the amount spent on y leads to a reduction in x which is equal to or greater than y. If y is spent without achieving any reduction in x (e.g., by inappropriate delivery mechanisms), then costs may be $x^s y^s C$.

Since C is always incurred, the real benefit possible is the difference between x and (x minus the results achieved by y).

The tricky part is to ensure that y actually does achieve the maximum reduction in x. Otherwise x will emerge as excesive social welfare costs as surely as damp emerges through plaster and wallpaper.

Costs of doing nothing. As Simkins notes, often in calculating the benefits and costs of various interventions, it is assumed that doing nothing incurs no costs. This is far from being the case with respect to persons with disabilities who are potential candidates for services delivered by transition programs. The costs of doing nothing--that is, ignoring alternative rehabilitative interventions--still mount up in the form of income transfer payments, health care, and other public subsidies.

Consider, for example, the costs of doing nothing in the case of a poor family with a severely mentally retarded youth who needs special help to become employed. If special help is not available, and the youth remained unemployed and totally dependent upon public support, the lifetime costs over a span of say 60 years would amount to hundreds of thousands of dollars in public subsidies.

Some Difficulties in Estimating Benefits

Control groups. Most informed policy makers are skeptical of "before and after" analysis in which the program participants serve as their own control group. It is difficult, if not impossible, to show that improvements by program clients in earnings and employment are the result of program experience and not from other causes such as changes in economic conditions, or the mere passage of time. Moreover, descriptions of the "before" situation may not actually be representative of the clients' general experience. To counter this problem, researchers have attempted to use control groups to isolate a program's effect on its participants.

Setting up an appropriate control group in rehabilitative programs can be exceedingly difficult. A number of concerns arise both for researchers and program administrators with respect to ethical and legal issues in holding back services for some for purposes of research. Despite these difficulties, researchers have searched for substitute control groups, which, while less than ideal does get at the problem to some extent. Included among these kinds of control groups are persons who were eligible for the program but did not apply; those who applied but did not show up; those who dropped out of the program; and friends and neighbors of program participants.

Lack of data. Lack of data is another problem encountered in estimating benefits of a program. The general practice has been to estimate the economic benefits of government programs by calculating the increases in client income that may be attributed to program experience. However, there are other intangible benefits that may accrue to society through reductions in maladaptive behavior, psychological satisfaction of the client and his or her family in being successfully employed, and general social benefits from greater participation in the mainstream of community life. Of course, since these intangible benefits do not lend themselves to quantification, they are difficult to measure.

Time frames. Other problems in estimating benefits (and costs) relate to the period of time over which they are to be considered. This involves the selection of a discount rate to calculate the present values of the streams of benefits and costs that will be received in future years. Discount rates, as well as the selection of the time horizon, are subjective and there appears to be little agreement among economists about how these should be determined. Consequently, economists take various approaches to handling the uncertainties of the future as they make assumptions and extrapolations. One of the most common methods of dealing with what might happen in the future is to make "best" estimates and "worst" estimates under varying assumptions with respect to labor market demands, wages, interest and other socioeconomic factors.

Despite the difficulties in estimating and comparing benefits and costs, such exercises are valuable because of the insights to be gained. Benefit-cost comparisons can provide useful insights for decision makers about resources allocation for transition programming. Benefit-cost analysis can suggest a number of clues for policy makers about how they might minimize program costs and maximize program benefits.

Cost Effectiveness Analysis

Cost-benefit analysis measures program benefits in economic terms. However, other measures such as functional improvement can be used to assess the effectiveness of a program. By and large, though, when these kinds of benefits are measured, but not formally entered into the calculations, the analysis is still referred to as cost-benefit analysis. However, when they are formally entered into the benefit calculations, either with economic benefits or separately, the analysis is usually referred to as a cost-effectiveness analysis. When cost-effectiveness analysis is done, the costs remain the same as in cost-benefit analysis but the measures of effectiveness that might be selected are limited only by the ingenuity of those examining the program.

Typical of the kinds of measures of effectiveness for transition programs would be such things as:

. Percentage of persons completing a program.

. Percentage of persons placed in employment.

. Functional improvement between pretests and post program tests.

. Opinions of satisfaction with the program by participants, parents, employers, and others.

Effectiveness measures are often ambiguous and hard to measure because values determined for various measures are arbitrarily selected and weighted. On the other hand, cost-benefit analysis can contribute in a more direct way to decision making because it is concerned primarily with effeciency in the use of resources. Economists, who comprise a large portion of active policy analysts, have had substantial influence on the development of cost-benefit analysis. It serves them by providing the most direct way to compute program efficiency by measuring the dollar value of inputs against the dollar value outputs of an activity.

Examining Some Newer Transitional and Supported Employment Programs

There are many efforts now underway throughout the country to create new vocational programs for persons with disabilities. I have selected five programs which appear to be representative of some newer kinds of efforts in transitional employment to examine their costs and benefits.

A word of caution is in order here. As we have seen, cost data and benefits derived are difficult to determine and the methodologies used to make calculations vary across programs. Nevertheless, it is useful to compare the costs of transition programs with each other and with other employment programs. From the standpoint of the participant, it is important to know whether possible increases in employment, earnings, and independence outweigh the potential loss of public benefits such as cash transfers and medical care. For the taxpayer, it is important to determine whether taxes eventually paid by program participants together with any reduction in their use of other publicly supported services makes transition programs a wise economic investment. From the broader social perspective, it is important to assess the overall effect of transition programming on the value of goods and services available to society as a whole.

In the sections that follow, we will examine the costs and other economic considerations of these newer programs:

1. Structured Training and Employment Transitional Services (STETS).
2. Virginia Commonwealth University - Rehabilitation Research and Training Center, Supported Competitive Employment Program (VCU - RRTC).
3. Specialized Training Program (STP).
4. The Vermont Transition Projects.
5. Washington Food Service Vocational Training Program (FSVTP).

STETS

The Manpower Demonstration Research Corporation (MDRC) coordinated the implementation of five transitional employment projects which were operated from the fall of 1981 through December, 1983 in New York, Cincinnati, St. Paul, Tuscon, and Los Angeles.

STETS tested the ability of diverse organizations to operate a "transitional employment" program for 18- to 24-year-old mentally retarded young adults. The goal of the program was to prepare participants for competitive employment--that is, an unsubsidized job in the regular, primarily private sector work force. The transition to competitive employment was to take place gradually, usually within no more than a year.

Participants were initially assigned to closely supervised, low-stress jobs in sheltered workshops and nonprofit or public agencies. Once they had learned basic work habits, the participants entered more demanding on-the-job training positions, generally in local businesses. The performance standards expected of STETS workers were steadily increased (and the level of program support gradually withdrawn) until productivity reached competitive levels. At that point, the participants would be ready to become regular members of an employer's work force.

Data on benefits and costs of the STETS projects were collected and analyzed by contract with Mathematica Policy Research, Inc. of Princeton, New Jersey. The benefit-cost analysis compared the economic benefits generated by STETS with the costs of program operations. A comprehensive accounting framework was used to assign dollar values to all measurable impacts such as increased earnings and reduced dependence on publicly funded programs, as well as other costs associated with the program. Bangser (1985) reports that the public cost of training one person for a full year in the STETS' program was about $8,700. Since the participant's average length of stay was less than one year, the cost per participant was $7,550. These figures probably overstate the costs of an ongoing program because operating costs are likely to be much greater during the start up phases of a program.

Thornton and Maynard (1985) present Mathematica's accounting framework used to evaluate STETS in Table 1. This framework includes the social perspective, the participant perspective, and the taxpayer perspective. The social perspective is used to judge economic efficiency because it includes only those impacts that could affect the aggregate value of social resources. The participant perspective indicates whether participants, on the average, benefit from the program and could be expected to enroll voluntarily. Whether a subsidy will be required to operate the program is indicated by the taxpayer perspective. Assuming that a dollar of benefit or cost is equal for all persons in society, then the sum of the participant perspective and the taxpayer perspective will equal the social perspective. In other words, all transfers of benefits and costs between these groups will net out.

This general framework has also been used to assess other transitional programs including those operated by VCU - RRTC. Table 1 identifies the major costs and benefits of transitional and supported employment. Program costs are broken out as operations, payments to participants, and central administration. Benefits are determined to be the reduced use of other publicly supported programs and residential facilities, reduced transfer payments and their administrative costs, and increased taxes. Other intangible benefits that are difficult to measure in dollars are also included such as increased independent living.

A unique feature of STETS was its establishment of a control group for making comparisons with the experimental group. The control group was not a "no treatment" group, but was comprised of individuals who were either in school, a sheltered workshop or other program, or in contact with an agency serving disabled individuals. Thus, the control group represented persons who received a mix of vocational and other services that mentally retarded persons normally receive.

Table 1
Expected Benefits and Costs of a Transitional or Supported Employment Program by Analytical Perspective

Component	Social	Participant	Taxpayer-*
I. Program Costs			
Project operations	-	0	-
Payments to participants	0	+	-
Central administration	-	0	-
II. Output Produced by Participants			
Increased inprogram output	+	0	+
Increased out-of-program output	+	+	0
III. Other Programs			
Reduced use of:			
Sheltered workshops	+	0	+
Work activity centers	+	0	+
School	+	0	+
Job-training programs	+	0	+
Case management services	+	0	+
Counseling services	+	0	+
Social/recreational services	+	0	+
Transportation services	+	0	+
IV. Residential Situation			
Reduced use of:			
Institutions	+	0	+
Group homes	+	0	+
Foster homes	+	0	+
Semi-independent residential programs	+	0	+
V. Transfer Payments and Taxes			
Reduced SSI/SSDI	0	-	+
Reduced other welfare	0	-	+
Reduced Medicaid/Medicare	0	-	+
Increased taxes	0	-	+
VI. Transfer Administration			
Reduced use of SSI/SSDI	+	0	+
Reduced use of other welfare	+	0	+
Reduced use of Medicaid/Medicare	+	0	+
VII. Intangibles			
Preferences for work	+	+	+
Increased self-sufficiency	+	+	+
Increased variation in participant income	-	-	-
Foregone nonmarket activity	-	-	0
Increased independent living	+	+	+

Note: The individual components are characterized from the three perspectives as being a net benefit (+), a net cost (-), or neither (0). The taxpayer perspective includes all members of society who are not program participants.
Source: Craig Thornton and Rebecca Maynard, "The Economics of Transitional Employment," Princeton, N.J., Mathematica Policy Research, Inc., March, 1985.

Analysis of benefits and costs. Table 2 shows the estimated benefits and costs of STETS per participant during the 22-month observation period. After 22 months, all program operating costs had been incurred but it must be remembered that benefits (e.g., increased earnings and reduced use of workshops and other programs) could be expected to continue. The notion of a continuing stream of future benefits is geared to the timing of the breakeven point where the cumulative economic benefits equal costs. Although data collection stopped at the 22-month point, the impacts appear promising since they either remained steady or rose slightly between the 15- and 22-month points.

Bangser has summarized benefits and costs from each of the comprehensive framework's perspectives as follows:

- *Society as a whole: Benefits offset most but not all of the investment by the 22-month point, when costs still exceeded benefits by approximately $1,000 per participant. However, if the impacts found at 22 months could be sustained for as little as seven more months, cumulative benefits would exceed costs. Given the pattern of generally stable or growing impacts between the 15- and 22-month interviews, there is a strong likelihood that society as a whole will reap a positive financial return on its investment.*
- *Participants: Not surprisingly, participants gained from the STETS program by over $2,100 per person during the 22-month period. This reflects their compensation as STETS participants and their increased earnings after leaving the program, both of which exceeded the taxes they had to pay and their reduced public assistance. Benefits should continue to grow to the extent that future net income continues to exceed what it would have been in the absence of the program.*
- *Nonparticipants: At the 22-month point, benefits to nonparticipants (i.e., all the rest of society) had offset a significant portion of the cost they had paid to operate the program, but about $3,100 of this group's investment per participant had not yet been recouped. Impacts would have to be sustained at the 22-month level for about two and one-half more years (or longer if benefits accumulate at a slower rate) for the economic benefits to equal the costs.*

Taken together, the benefit-cost findings indicate that participants were already well ahead by 22 months after random assignment and that society as a whole would very likely be ahead within a short time. The situation for nonparticipants was less clear, since benefits would have to be projected further into the future to reach the break-even point.

VCU - RRTC

Mark Hill, Janet Hill, Paul Wehman, and David Banks (1985) at the Virginia Commonwealth University's Rehabilitation Research and Training Center used benefit-cost procedures similar to those used by STETS to study 140 mentally retarded individuals placed in competitive employment over a period of six years. These participants ranged from age 18 to 63 and were served by programs in Richmond, Norfolk, and Virginia Beach. The mean IQ score of participants was 50 with a range of 27 to 78. Eighty-six percent of the participants were receiving Supplemental Security Income (SSI) or other government subsidy at placement. During the year prior to placement, only 18 percent of the participants had earned more than $200 annual salary from sheltered or nonsheltered employment.

Table 3 summarizes the monetary outcomes associated with the VCU - RRTC competitive employment supported work program. As noted by Table 3 program benefits include increased earnings, fringe benefits, and taxes paid. Also, on the benefit side were reduced use of other publicly sup-

Table 2
Expected Benefits and Costs of STETS Per Participant During The Observation Period, Basic Estimates
(1982 dollars)

	Component	Social	Participant	Nonparticipant
I.	**Program Costs**			
	Project operations	-$6,050	$0	-$6,050
	Payments to participants	0	3,094	-3,094
	Central administration	-182	0	-182
II.	**Output Produced by Participants**			
	Phase 1 and Phase 2 output	3,434	0	3,434
	Foregone output while in STETS	-425	-425	0
	Increased out-of-program output	268	268	0
III.	**Other Programs**			
	Reduced use of:			
	Sheltered workshops	767	0	767
	Secondary vocational school	428	0	428
	Other school	112	0	112
	Job-training programs	434	0	434
IV.	**Residential Programs**			
	Reduced use of:			
	Institutions	174	0	174
	Group homes	72	0	72
	Foster homes	7	0	7
	Semi-independent residential programs	-114	0	-114
V.	**Transfer Payments and Taxes**			
	Reduced SSI/SSDI	0	-264	264
	Reduced other welfare	0	-82	82
	Reduced Medicaid/Medicare	0	-232	232
	Increased taxes	0	-249	249
VI.	**Transfer Administration**			
	Reduced use of SSI/SSDI	16	0	16
	Reduced use of other welfare	8	0	8
	Reduced use of Medicaid/Medicare	12	0	12
VII.	**Intangibles**			
	Preferences for work	$	$	$
	Increased self-sufficiency	$	$	$
	Increased variation in participant income	-	-	-
	Foregone nonmarket activity	-	-	-
	Increased independent living	$	$	$
Net Present Value (Benefits less Costs)		-$1,038	$2,111	-$3,149

Note: Benefits and costs are discussed to the time of enrollment using a 5 percent real annual discount rate.
Source: Stuart Kerachsky, et. al., The Impacts of Transitional Employment for Mentally Retarded Young Adults, Mathematica Policy Research, Inc., Princeton, N.J., (p. 161).

ported programs such as workshops and day care, along with decreased government subsidies such as SSI and health care.

Costs were identified as operational costs of the program, decreased workshop earnings, decreased government subsidy, and taxes paid by the client. As in the STETS framework, VCU - RRTC explains the distribution of costs among three perspectives as follows:

Society and the taxpayer must pay for the supported work model, society also loses the small sheltered workshop earnings the client could have brought in if s/he were attending a workshop. The client, in essence, pays the most, however, in 1) loss of government subsidy (SSI/Medicaid); 2) contribution of taxes and 3) loss of sheltered workshop earnings. VCU - RRTC believes that a competitive job would in most cases make up for these losses.

VCU - RRTC identified actual monetary benefits and costs for 140 participants over a six-year period from permanent records and information provided by cooperating agencies.

Summary of benefits. As shown in Table 3, increased earnings per participant averaged $6,209 with $803 added by fringe benefits. These benefits accrued both to society and the individual participant. Taxes paid by participants averaged $1,392 and are considered to be a benefit to other taxpayers. Decreased use of alternative programs was calculated to be $4,226 which benefited general society as well as taxpayers. Decreased government subsidy in the form of SSI was determined to be $2,342 per participant.

Lower costs for health care were calculated to be $336 per participant. Taken together, decreases in SSI and health care costs benefit taxpayers.

Total average benefits which accrued to society during the demonstration period were $11,278; for participants, $7,012; and for taxpayers, $8,336.

Summary of Costs. Table 3 shows that the program cost society and taxpayers an average of $5,485 per participant. This amount was derived by dividing the 140 participants placed in employment into total program costs of $767,900. Decreased workshop earnings were also calculated as costs to individual participants and society in the amount of $864. VCU - RRTC based these calculations on a study done by the U.S. Department of Labor in

Table 3
Monetary Outcomes Associated With a Competitive Employment Supported Work Program for Persons Labeled Mentally Retarded
(Rehabilitation Research and Training Center)
(Virginia Commonwealth University)
May 1978 - February 1984

	Societal	Participant	N = 140 Taxpayer
1. Benefits			
A. Increased Monetary Output			
1. increased earnings	$6,209	$6,209	$----
2. fringe benefits	803	803	
3. taxes paid/collected	----	----	1,392
B. Decreased Use of Alternative Programs	4,266		4,266
C. Decreased Government Subsidy			
1. decreased SSI	----	----	2,342
2. decreased health costs	----	----	336
Subtotal	11,278	7,012	8,336
2. Costs			
D. Operational Costs	-5,485		5,485
E. Decreased workshop earnings	-864	-864	----
F. Decreased Subsidy			
1. loss of SSI	----	-2,342	----
2. increased health costs	----	-336	----
G. Taxes Paid	----	-1,392	----
Cost Total	6,349	-4,934	5,485
Total Benefit	11,278	7,012	8,336
- Total Cost	-6,349	-4,934	-5,485
= Per Participant Net Value After 70 Months of Operation	+4,929	+2,078*	+2,851
Group Value (N=140)	690,060	290,920	399,140
Yearly Benefit Breakdown	$118,976	1,308**	60,706

*Mean Months Employed for Study Population = 19 months

**(Net Participant Value/Mean Months Employed X 12 Months = Yearly Per Participant Net Value)

Source: Mark Hill, et. al., **Competitive Employment for Persons With Mental Retardation**, Richmond, Virginia, VCU - RRTC, Volume 1, 1985, (p. 132).

1977 which showed the mean annual income for workshop workers to be $414. After adjusting for inflation, VCU - RRTC calculated lost workshop income to participants and society as a cost to them of $48 per month, or $576 per year. Additional costs to participants through the loss of SSI and increased health costs were $2,342 (SSI) and $336 (health care). Moreover, participants paid taxes which amounted to a mean cost of $1,392. The total costs for society were $6,349; for participants, $4,934; and for taxpayers, $5,485.

The bottom line. VCU - RRTC calculated the bottom line benefits as exceeding program costs for each of the three perspectives as follows (based on yearly benefits):

Perspective	Net Monetary Benefits
Society	$118,976
Participant	1,308
Taxpayer	60,706

STP

The Specialized Training Program at the University of Oregon's Center on Human Development is concerned with comparing new models of supported employment with traditional services in sheltered workshops and day activity programs. The employment models developed by STP focus on wages and work related benefits to program participants and attempt to enhance social integration of persons with severe handicaps in the workplace. STP models are described as enclave, supported jobs, mobile crew, and benchwork. (Mank, Rhodes, and Bellamy, 1985).

Enclave model. The enclave model is being developed near Seattle, Washington by the cooperative efforts of an electronics firm, Physio Control, together with STP, Trillium Employment Services, and the Divisions of Developmental Disabilities and Vocational Rehabilitation in the State of Washington. Enclave workers have the same 10-hour day and four-day work week as other employees in Physio Control and receive holiday pay, sick leave, and vacations. STP reports average monthly earnings of six severely disabled workers in October, 1984 of more than $400 per person.

Table 4 shows a summary of earnings of the enclave workers for the first eighteen months of the demonstration through February 28, 1985. The average monthly wage earned by these workers prior to their employment at Physio Controls was $44. By the end of 18 months at Physio Controls, they had increased their average earnings to $352 each. (Rhodes and Valenta, 1985.)

Supported jobs model. The supported jobs model places moderately and severely retarded individuals in jobs by a not-for-profit service organization which provides continuing support needed to maintain the person's employment. This model is being demonstrated in Eugene, Oregon by the cooperative efforts of STP, McKenzie Personnel Systems, and the Lane County Community Health and Social Services.

All individuals participating in this demonstration project have measured IQ scores below 50 and have been placed in jobs at a bakery, retirement center, restaurant, bank, and hotel. The costs of the supported jobs model are not yet known, but are expected to be similar to day activity programs. The average wage of program participants during January, 1985 was close to $250. (Berendt, 1985.)

Mobile crew model. Typically, five crew members and a supervisor operate from a mobile van and perform service work such as custodial and grounds maintenance. Such crews have start up costs of about $5,000 to $8,000 for planning and acquiring equipment needed to implement service contracts. STP reports wages of $130 to $185 per month for individual workers. Of course, extra costs are incurred in this model because workers do not function at full productivity and require more supervision than other workers without disabilities. (Collins, 1985.)

Benchwork model. The benchwork model was developed in the early 1970s as an alternative to conventional day activity programs. Contract work in this model is procured from electronic firms and related enterprises to do assembly work. Typically, the benchwork model employs one supervisor to five workers, and is located within, or near, the parent firm for which it performs services under contract.

From a cost perspective, large capital investments are not required, and the need for space and equipment is minimal. Start up costs for establishing a benchwork company normally range from $15,000 to $25,000. Principal costs are to hire and train staff and to buy initial equipment needed to begin operations. STP reports wage earnings in the benchwork model to average $118 per month for individual workers.

Comparing STP models. Table 5 compares costs, wages, and other employment benefits of the four models discussed. Although the enclave model appears to be superior with respect to benefits and costs, as noted by STP, no single alternative is a panacea for transition to work. In most communities, there are situations with employment potential that can be exploited by using a number of different approaches.

Table 4
Individual Employee Summary
First 18 Months, Ending February 28, 1985

Employees	Age	Previous Employment Status	Recorded[1] 10	Months Employed Physio	Avg. Monthly Wage Prior to Physio	Avg. Monthly Wage at Physio	Total Wages	Status
1	32	Work Activity Center	45	18.5	$26	$306	$5,656	Trillium Employee
2	38	Work Activity Center	44	.5	19	N/A	130	Terminated (2 weeks)
3	39	Work Activity Center	43	17.5	35	490	8,575	Physio Employee
4	25	Work Activity Center	39	4.5	44	292	1,314	Terminated (4 months)
5	27	Work Activity Center	44	17	110	305	5,192	Trillium Employee
6	31	Work Activity Center	37	16	26	314	5,020	Trillium Employee
7	31	Unemployed (18 months)	33	15	-0-	458	6,873	Physio Employee
8	23	Unemployed (7 months following graduation)	43	12.5	-0-	303	3,792	Trillium Employee
Mean	31			12.69	$44[2]	$352	$4,569	

[1] Most recent Wechsler or Stanford-Binet on record.

[2] Mean based on six workers employed by work activity centers prior to entering Physio.

Source: Larry E. Rhodes and Lee Valenta, "Enclaves in Industry," to be published in **School to Work Transition for Youth With Severe Disabilities** (eds.) P. McCarthy, J. Everson, S. Moon, and M. Bareus, VCU - RRTC, Richmond, Virginia.

Vermont Transition Projects

The Vermont transition projects have been developed in Barre (I), Burlington (II), White River Junction (III), and Rutland (IV), during the past five years. These programs provide training, placement, and other services needed to assist persons classified as mentally retarded and severely disabled to obtain competitive employment in the open community. Typically, these persons leave public school special education classes and enter day programs on work activity programs associated with regional mental health centers. These individuals are usually considered unemployable by conventional vocational rehabilitation programs.

The Vermont projects are funded by a variety of sources such as vocational rehabilitation, mental health, fees for service, and federal grants. The projects are patterned after the work of Rusch, Mithaug and Wehman. Typically, each project employes a staff of three and is expected to provide competitive employment placements for at least 12 project participants during a year's time. These projects are operated by the cooperative efforts of the University of Vermont, Trinity College, and mental health services from Washington, Chittenden, Windsor, and Rutland counties.

Vogelsberg (1985) reports that about half of the placements have been in service occupations

Table 5
Comparison of Costs, Wages, and Other Employment Benefits In STP Supported Employment Models

	Supported Jobs	Enclave	Mobile Crew	Benchwork
Cost	(Not yet known), expected to be similar to day programs	Less than half the day programs	Same as traditional day programs	Same as traditional day programs
Wages Earned	Medium. $210 per month	High. $295 per month	Medium. $185 per month	Medium. $118 per month
Other Employment Benefits	Medium. Benefits vary across jobs.	High. Full insurance benefits for workers after hiring by company.	Low. Job security and benefits depend on organization's commercial success.	Low. Job security and benefits depend on organization's commercial success.

Adapted from: David M. Mank, Larry E. Rhodes, and G. Thomas Bellamy, "Four Supported Employment Alternatives," submitted for publication in **Pathways to Employment for Developmentally Disabled Adults** edited by W. Kiernan and J. Stark, Baltimore, Paul H. Brooks, 1985.

(custodial and kitchen) while the remainder have been in a wide variety of locations. The best paid position is $9.58 per hour. As of June, 1985, 89 individuals were working as a result of project efforts at an average monthly wage of $353. They have compared these wages with an average salary of $417 per year for individuals with mental retardation who work in sheltered workshops.

In February, 1985 the transition projects were costing about $6,500 per year per participant. The cost for one year in an adult day program in Vermont is $5,000. However, as each project continues to place individuals the cost effectiveness improves. Moreover, it should be emphasized that these costs are not a continuing annual cost, but a one-time cost for those 65 percent who are successful in their jobs. In addition, there are both monetary and nonmonetary benefits that also accrue to offset project costs (Vogelsberg, Patterson, and Ashe; 1985).

Table 6 reflects the track record for each of the four Vermont projects in terms of monetary benefits yielded for the participants as well as government savings from reductions in payments by supplemental security income (SSI) and social security disability benefits (SSDB). As indicated by Table 6, total salaries earned in the projects are $394,884 over the reporting periods of 61 months for Project I; 36 and 9 months for Project II; 14 months for Project III; and 3 months for Project IV. Approximately $40,196 in social security benefits have been saved as well savings in day program costs of $287,145 (Vogelsberg, 1985).

Table 7 (Vogelsberg and Ashe, 1984) indicates a measure of cost effectiveness of the first project in Barre. The total program costs compared to the gross benefits show that after close to three years of operation the project returned as much to society in salaries and savings in SSI, SSDB, and day care costs as it required from the social service system. After this break-even point, benefits exceed the costs as the program continues.

The Washington Food Service Vocational Training Program

The Washington Food Service Vocational Training Program (FSVTP) is one of the oldest of the more modern transition programs. It began in 1975 at the University of Washington with the assistance of grant support by the U.S. Department of Health, Education, and Welfare. A main purpose of the project was to find alternatives to sheltered workshop employment for severely and moderately retarded individuals by assisting them for entrance into competitive employment. The program provides preemployment training in two campus cafeterias at the University of Washington for entry level food service jobs. The trainees are then placed into competitive jobs in the Seattle area that pay minimum wage or more. On the job training is provided and follow up services are available "forever." (Dineen, 1985.)

Table 6
Financial Information (Total Salaries $394,884)

Type of Employer Assistance	Fringe Benefits	Range of Pay Per Hour	Range of Monthly Salaries	Range of Preemployment Benefits	Range of Postemployment Benefits
30 TJTC* 22 None 5 CETA* 3 NARC*	49 Vacations 13 Insurance 9 Sick Days	*$3.10-6.05 X = $3.55 Mon = $3.35 13 Raises (30%) *Minimum Wage 1980	$20-660 X = + 338 Mon = $335 Total Salaries To Date = $248,796	SSI 18 Recipients $3-457 X = $272 SSDB 14 Recipients $81-789 X = $362	($24,202 savings) 13 Recipients $2-385 X = $183 (SO savings) 13 Recipients $81-878 X = $383
Project Transition I: 4/1/80-5/1/85 (61 Months)					
18 TJTC* 11 None 1 Public School 53% initiated Benefits	12 Insurance 10 Vacations 4 Sick Days	$3.35-9.58 X = $4.05 Mon = $3.35 5 Raises (20%)	$27-1,540 X = $400 Mon = $300 Total Salaries To Date = $116,575	SSI 18 Recipients $25-468 X = $312 SSDB 7 Recipients $157-319 X = $267	($12,395 savings) 16 Recipients $1-458 X = $237 (SO savings) 7 Recipients $157-319 $258* *Cost of Living Increase
Project Transition II: 11/1/81-11/1/84 (36 Months)					
8 TJTC*	3 Insurance 3 Vacations 1 Sick Day	$3.35-5.00 X = $3.64 Mon = $3.50	$123-323 x = $280 Mon = $288 Total Salaries To Date = $8,414	SSI 7 Recipients $117-468 X = $298 SSDB 4 Recipients $111-245 X = $215	($2,468 savings) 7 Recipients $117-432 X = $235 (SO savings) 4 Recipients $111-245 X = $215
Project Transition II: 10/1/85-6/1/85 (9 Months)					
11 TJTC* 5 NARC* 1 None	6 Insurance 5 Vacations 4 Sick Days	$3.35-4.40 X = $3.59 Mon = $3.75 5 Raises (33%)	$58-624 X = $356 Mon = $331 Total Salaries To Date = $19,921	SSI 5 Recipients $181-488 X = $294 SSDB 4 Recipients $210-494 X = $345	($1,101 savings) 4 Recipients $120-358 X = $192 (SO savings) 4 Recipients $210-494 X = $345

Project Transition III: 3/1/84-5/1/85 (14 Months)

2 TJTC* 1 NARC*-OJT* 1 None	3 None	$3.35-3.50 X = $3.45 Mon = $3.50	$134-225 X = $186 Mon = $198 Total Salaries To Date = $1,178	SSI	
				3 Recipients $112-483 X = $297	3 Recipients $78-483 X = $276
				SSDB	
				2 Recipients $236-285 X = $260	2 Recipients $236-285 X = $260

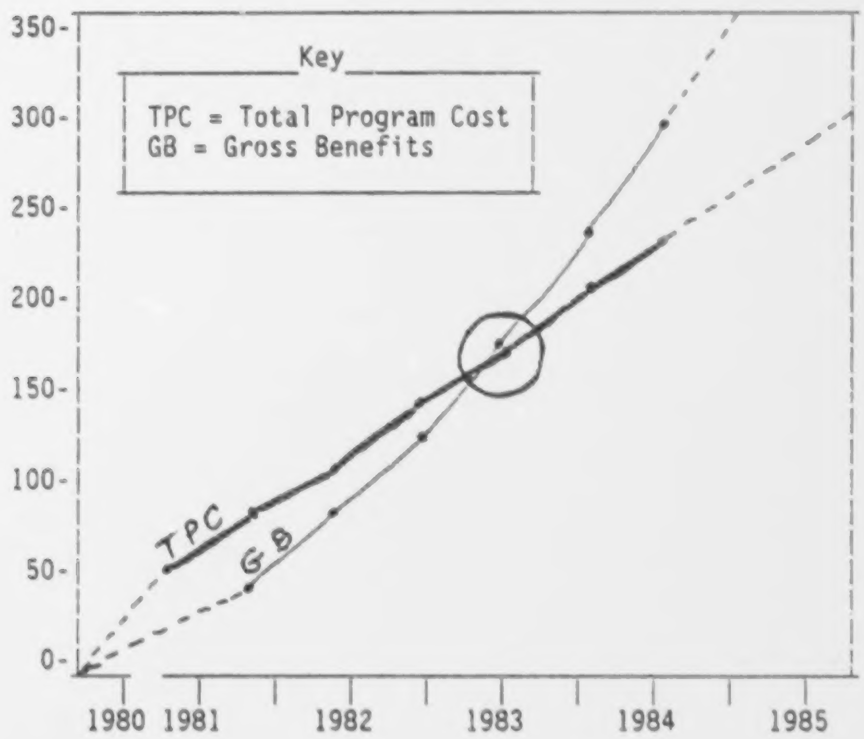
Project Transition IV: 2/1/85-5/1/85 (3 Months)

Source: David Pitonyak, Department of Special Education, Social Work, and Social Services, University of Vermont, Personal Communication, October, 1985.
*TJTC - Targeted Jobs Tax Credit
*CETA - Community Employment & Training Administration
*NARC - National Association of Retarded Citizens
*OJT - On-The-Job-Training

An amazing amount of data has been collected during the past ten years on every individual who has ever been a participant in the Washington program. Data includes client demographics, places employed, types of jobs performed, time in training, time employed, and individual training costs and earnings. JoAnn Sowers, Linda Thompson, and Richard Connis reported on training costs after about three years of program operations (Bellamy, O'Conner, Karan, 1979). They calculated the

Table 7

Cost Effectiveness of Project Transition in Barre, Vermont



average program cost at the period of development to be about $12,250 per month. These expenditures were broken down as follows:

$9,528 - monthly costs for program director, coordinator of training, four training analysis, secretary, travel, supplies, equipment.

2,722 - monthly costs for followup staff, i.e., coordinator, training analyst, travel, supplies, equipment.

$12,250 - total monthly program costs.

During this period the program had accepted 33 participants and had placed 17 of those into jobs. The duration of in-house training for those employed at that time ranged from two to 18 months. The costs per trainee ranged from $1,190 to $10,710. The average training time required for competitive employment was six months. This amounted to an average cost of $3,520 to train an individual for competitive employment. The FSVTP staff noted, that by comparison, the costs of maintaining one individual in a sheltered workshop at that time (around 1979) was about $5,000 per year--a continuing cost.

As of May 31, 1985 the FSVTP had placed 107 trainees into competitive employment in the Seattle area. Of the 107 placed, 51 are presently employed. The total gross earnings of these workers has been calculated at $1,495,114. Table 8 shows the costs for 56 trainees who were employed as of May 31, 1985. Total training costs for these individuals was $570,248 for an average cost per person of $10,183 which spans a period of almost 10 years.

Summary of Transitional Program Costs

It is somewhat difficult to make cross comparisons of the costs of the transition programs we have examined. Each one is in a different economic environment, and their goals and techniques, while similar in some respects, do vary. Data also varies in the kinds and amounts collected as well as the timing of the collection. Table 9 is an attempt to summarize and compare costs of the programs including STETS, VCU - RRTC, STP, the Vermont Transition Projects, and the Washington FSVTP. These costs will show variations from time to time depending, of course, on the number of clients participating in the programs and routine fluctuations in their budgets.

Table 8
Costs For Currently Employed Trainees
STATS1 5/31/85

# Months on Present Job	Trainee Code #	Age	IQ	Months in Training	$ For Training	# Jobs	$ For Follow	$ Current Month	Total Spent
More Than 9 Years	003	31	58	4	2,382	1	1,415	12	3,795
More Than 8 Years	004	28	91	5	2,975	2	6,028	8	9,003
	010	43	51	4	1,745	2	4,418	0	6,163
	016	35	55	2	1,190	3	2,457	32	3,647
More Than 7 Years	007	34	53	18	10,710	1	3,916	8	14,625
	031	34	71	2	1,190	1	4,619	8	5,809
More Than 6 Years	028	45	60	7	4,165	2	2,324	8	6,489
	015	45	30	23	13,685	1	2,545	224	16,230
	033	30	30	10	5,080	2	2,308	0	7,388
More Than 5 Years	038	30	47	14	8,635	1	1,510	32	10,145
	046	26	50	13	8,505	1	3,077	2	11,508
	047	29	41	18	12,295	1	3,625	20	15,920
More Than 4 Years	059	27	64	12	8,870	1	1,303	38	10,173
	052	26	31	20	13,915	2	5,380	0	19,295
	068	32	46	10	7,818	1	886	32	8,689
	061	26	59	17	13,220	1	4,600	260	17,820
More Than 3 Years	902*	26	55			1	87	28	87
	084	26	71	7	5,792	1	4,487	106	10,279
	901*	24	45			1	158	0	158
	051	27	52	16	10,475	5	1,403	0	11,908
	056	26	51	17	11,470	3	1,385	12	12,855

More Than 2 Years	066	27	48	13	7,595	2	6,641	104	14,236
	092	25	42	10	9,000	2	3,438	0	12,438
	045	41	54	8	4,560	3	2,930	4	7,490
12-24 Months	095	24	41	3	2,577	3	5,668	50	8,235
	909*	32				1	1,740	60	1,740
	121	24	50	10	8,080	1	3,011	12	11,091
	130	44	60	6	4,686	1	1,135	48	5,821
	122	21	90	10	8,900	1	4,180	20	13,080
	133	22	67	5	4,455	1	10,086	208	14,526
	075	27	56	12	9,625	2	3,313	28	12,938
	123	24	52	13	10,580	1	1,554	16	12,120
	125	34	51	13	10,700	1	3,807	20	14,507
	108	23	69	16	11,500	2	5,284	132	16,784
	115	24	55	15	10,710	2	4,349	100	15,059
	139	22	66	7	5,691	1	936	24	6,630
6-12 Months	137	19	52	10	8,128	1	2,039	252	10,167
	074	28	52	22	14,718	3	3,926	171	18,644
	156	21	69	1	832	1	1,745	38	2,497
	099	24	40	14	7,764	4	3,645	4	11,417
	012	28	52	7	4,164	3	3,821	28	7,985
0-6 Months	053	26	47	9	5,145	3	8,210	20	13,335
	093	23	41	18	12,550	3	9,270	114	21,543
	027	28	50	10	5,355	5	7,406	0	12,831
	069	36	54	22	12,250	4	9,056	76	21,306
	126	25	69	2	1,165	2	6,072	0	7,237
	086	31	44	20	14,900	2	3,700	4	18,500
	141	25	63	14	10,571	1	768	8	11,339
	043	24	61	13	8,095	5	3,055	52	11,150
	910*	37	50			2	1,901	70	1,901
	118	23	48	12.5	8,774	4	1,948	20	10,724
	152	21	45	7	5,876	1	5,480	508	10,377
	146	49	62	5	4,145	2	2,484	60	6,729
	142	24	40	15	12,533	1	3,750	1075	2,583
	089	22	69	22	14,700	4	10,903	528	6,073
	048	35	61	5	3,045	3	3,998	1468	7,043

Mean Age = 28.8   **Mean Total Cost** = 10,183
Mean IQ = 53.2   **N=52 (*4)**

Source: John Dineen, University of Washington, Employment Training Program, Seattle, Washington, Personal Communication, October, 1985.

The range of average expenditures per client year in these programs is from $1,760 to $12,352. The average expenditure per participant ranges from $4,613 to $10,396. It seems reasonable to expect that future transition programs, generally speaking, would cost between $5,000 and $6,000 per year. In many instances, these kinds of programs would not necessarily cost less than traditional day programs or sheltered workshop programs. Rather, the anticipated advantage of the newer transition programs lies in the greater monetary and nonmonetary benefits that they yield.

When compared with other kinds of employment programs, the transition demonstrations appear to be in an acceptable range of costs. Thornton and Maynard (1984) report some results obtained by Taggart from a survey of some U.S. Department of Labor Programs in 1981. The following costs were found:

Program	Average Expenditure per client year	Average Expenditure per participant
Job Corps	16,493	8,384
Work Experience (CETA)	6,642	2,052
Public Service Employment (CETA)	11,292	4,630
On-The-Job Training (CETA)	7,613	2,049

Policy Implications

The analysis and calculations in the experimental transition programs we have examined produce a number of implications for public choices about allocating resources to assist severely disabled persons to obtain competitive employment. The most obvious implication concerns the size of both

Table 9
Average Operating Expenditures for Transitional Programs
(based on 1985 reports)

Program	Average Expenditure per client year	Average Expenditure per participant
STETS (Thornton & Maynard, 1984 dollars)		
Cincinnati	11,107	9,070
Los Angeles	9,418	7,848
New York	12,352	10,396
St. Paul	5,828	4,613
Tucson	7,243	7,605
Average for all participants		8,136
(Bangser, 1985)	8,700	7,550
Virginia Commonwealth University: Rehabilitation Research & Training Center (Hill, et. al, 1985)	3,657	5,485
STP (Rhodes, et. al., estimates only) with day program range 3,000-6,000)		
Supported Jobs (not known, expected to be similar to day program costs)		
Enclave (less than half day program costs)		
Mobile Crew (same as traditional day program costs)		
Benchwork (same as traditional day program costs)		
Vermont Transition Project (Vogelsberg, 1984)*		
Barre	6,511	N/A
Burlington	7,215	N/A
White River Junction	N/A	N/A
Rutland	N/A	N/A
Washington FSVTP (Dineen, 1985)**	1,760	10,183

Note: N/A means not available.

* As each Vermont project continues to place individuals, the cost-effectiveness improves. These cost figures are not a continual yearly cost, but a one time only cost for those 69 percent who are successful on the job. White River Junction and Rutland are new programs and are expected to cost about the same as Barre and Burlington.

** Average expenditures per client year based on an average cost of $3,520 for each individual, but which required only six months for training and placement. The other figure (10,183) covers expenditures over a period of almost 10 years).

monetary and nonmonetary gains yielded from newer concepts and methods to prepare these individuals for real jobs in the community. Other considerations include costs of administering and operating employment and training programs for persons whose disabilities are severe. It is one thing, however, to mount a demonstration project and quite another to translate its findings into policy reform. Unless improved public policies result from these recent experimental efforts; and until their newer techniques are widely implemented, they will have been interesting exercises, but largely academic.

Howell S. Baum (1980) has suggested that one barrier to the effectiveness of practitioners in policy analysis is that they tend to emphasize the techniques they wield rather than on the problems to which these techniques might be applied. He contends that those who would influence policy decisions need to replace their focus on technique as problem solving with a broader perspective. This broader view would recognize that the social problems with which they are concerned are extensive, complex, and poorly bounded. Further, the policy problems are implicated in a web of perceived interests and the remedies lie in strategies for organizing coalitions of those interests for particular courses of action. What is required for greater influence in policy making is to define the relevant policy space and issue area; identifying interested actors, their beliefs, motivations, and resources; locating crucial decision sites; projecting likely areas of concensus and confict; and anticipating errors.

Transition programs depend heavily on coordination among different human resource agencies and a wide array of professional service providers. Janet A. Weiss (1981) has cautioned us about the pitfalls of coordination. In the first place our human services system has developed in fits and starts by responding to the needs of various groups at different times. As a result, we have a vast, complex system supported by enormous budgets, dispersed responsibility, fragmented funding and service structures, and inaccessible, unresponsive, discontinuous service delivery.

Weiss observes that the most common mistake in planning for improved coordination is underestimating the inertia in the system and expecting large impacts from relatively small changes. When coordination efforts begin, the vague notion that coordination will be effective often masks the multiple, conflicting hopes and expectations that clients, politicians, administrators, professional service providers, and interest groups each cherish independently. This result in a persistent lack of consensus and clarity over what programs are supposed to do and how much they are expected to accomplish.

A principal source of resistance to coordination and policy reform are the professional service providers who must change their daily work behavior if the service delivery system is to be changed in any meaningful way. Transition programs make use of many different kinds of professionals--counselors, social workers, mental health therapists, teachers, trainers, psychologists, and so forth. Their training and experience varies, and they see client and community problems in different ways. Each specializes in certain kinds of techniques to treat certain kinds of problems in their own way. Moreover, as professionals, they are guardians of quality in the delivery of services which tends to arouse suspicions about changes imposed by others who may be outside their particular disciplines.

Despite the many barriers to effective program coordination and policy reform, the application of benefit-cost analysis and cost-effectiveness analysis appear to be promising analytical techniques for the continuing development of transition programs. Educational, mental health, and vocational rehabilitation services are expressions of political purposes and reflect the pluralistic nature of those purposes that must compete for scarce resources. While it is probably true that resource allocation decisions are largely politically-based, it appears that courses of action are seldom taken by decision makers until numerical estimates are examined and discussed.

Decision makers who formulate public policy do not start from a clean slate. They are keenly aware that in policy making you start from where you are. The Office of Technology Assessment of the U.S. Congress (1983) recommends that regardless of the kind of formal analysis the policy maker uses to aid in decision making, certain principles of analysis should be followed. Program operators, as well as those involved in researching and demonstrating the effectiveness and efficiency of transition programs, might consider these recommended principles as they plan new initiatives for expansion. Influencing policy decisions and resource allocations might be enhanced by incorporating these principles with other aspects of program planning. The purpose is to consider in advance a basis for structuring policy decisions so that program data can be collected, analyzed, and reported in a way which will facilitate future policy formulation at higher administrative and political levels.

If transition programs could be designed and discussed within the policy context suggested by these principles, it should result in greater impact on policy making. These ten principles are:

1. **Explicitly define the problem.** Unless the problem is explicitly stated and adequately understood, resources cannot be effectively applied. Goal statements about limited program aims are not enough. A clear examination of the situation or underlying problem to be addressed is essential to the policy development process.
2. **State the objectives in measurable terms.** Beware of high percentage placement objectives that pay little attention to length of ensuring employment, level of earnings, and other substantive outcomes. Transition program administrators and researchers can transmit signals to policy makers about the importance of various outcomes by the way their objectives are specified.
3. **Identify the alternatives.** Researchers and program administrators can influence resource allocation decisions by helping policy makers identify the range of possible decisions in addressing a policy problem. They should consult with disabled persons and others in determining possible alternatives, and they need not confine themselves to only thinking about those options that are strictly within their mandate. They should also help policy makers identify how costs and benefits of various alternatives would be distributed.

4. **Analyze the positive consequences.** Resource allocation decisions can be influenced by identifying and measuring who will benefit from program alternatives and what benefits might be expected.
5. **Analyze the negative consequences.** This refers to the costs of various alternatives, who pays, and how much.
6. **Differentiate the perspective of the analysis.** Resource allocations can be influenced by providing better information about benefits and costs of programs from the perspective of all interested parties. A desirable, but frequently ignored aspect of policy, and program planning is involving the principal stakeholders in analyzing the relationships among those who would benefit and those who would incur costs.
7. **Perform discounting.** Time and uncertainty about the future affect the estimates of potential outcomes of any program. Since people value having things now more than they value having the same things in the future, the discount rate represents the value of foregone opportunities for another investment. Discounting is a way of applying a reverse interest rate for transforming future amounts of benefits and costs to their present value of today.
8. **Analyze uncertainties.** Every decision to allocate resources is made with some degree of uncertainty. Transition program administrators and researchers can enhance the understanding with which these decisions are made by identifying sources of uncertainty which might seriously affect desired program outcomes and estimating their probable effects.
9. **Address ethical issues.** There are no magic answers to the problem of taking into account subjective and value laden aspects of resource allocation. Since resources are not allocated solely on the basis of expected net returns on dollars invested, and include consideration of ethical issues as well, transition programs should avoid single, bottom-line estimates of outcomes.
10. **Present and discuss results in a policy context.** If certain kinds of transition programs are more effective and efficient than others, policy makers need to be informed about this. Of course, program results cannot be assessed unless adequate mechanisms are in place to collect and analyze data. Although each of the experimental programs we examined had fairly extensive ways and means for self-evaluation, there are no common patterns of data aggregation which might be more useful for national policy making. Perhaps those now involved in designing and operating newer kinds of transition programs could agree on specifications that would lead to a comprehensive national data base.

Reinforcing economic arguments. Mary Switzer was a native of Massachusetts, but during her years of national rehabilitation leadership she lived in Alexandria, Virginia. On occasion, she would attend our staff meetings in the State rehabilitation agency. I gained a strong impression during those exchanges that she was indeed a woman of practicality. As a public administrator, her programmatic approach toward influencing policy decisions with economic arguments was well established. In addition to moral and ethical issues, she emphasized benefit cost relationships as a practical way to educate policy makers at the highest levels about vocational rehabilitation. Her record of legislative accomplishments attests to her success in this area.

We still have a great deal to learn about the economics of disability and the benefits and costs of transition programs. The contribution of benefit-cost analysis has been limited by lack of agreement in methodology, a shortage of skilled persons qualified to perform these studies, the lack of funds for conducting benefit-cost research, and the fear of some program advocates that the outcome of such studies might be unfavorable to their vested interests. Nevertheless, determining the benefits and costs of alternate rehabilitation strategies has much potential for increasing the efficiency with which resources are used in transition programs.

To conclude, I would like to strike a blow for increased efforts to apply benefit-cost analysis in transitional programming. To be sure, it is only one approach to evaluation, and there are times when other evaluation techniques might be more appropriate. However, a main virtue in benefit-cost analysis, I think, is its comprehensiveness. This enables program administrators to see their programs in a larger social and economic context and can reinforce their economic arguments to influence policy decisions. Benefit-cost analytical exercises, alone, are instructional. They provide rehabilitation administrators with greater insights to their programs by helping to clarify the relationships among program inputs, processes, and outcomes.

Moreover, benefit-cost analysis provides policy makers with valuable information about equity and economic efficiency in the distribution of public resources. And finally, although most resource allocation decisions are essentially political judgment, these decisions are seldom made until hard figures enter the discussions. Benefit-cost analysis makes for a commonsense approach to the inclusion of hard data in policy decisions.

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EXCERPTS OF REVIEWS AND COMMENTS

The following are excerpts of reviews, comments and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as it relates to the content of Chapter Four by Dale Hanks.

Benefit-cost analysis have severe limitations which need to be stressed. Strictly speaking, to carry out a benefit-cost analysis, all benefits and costs must be identified and quantified in dollar terms so that they can be summed and compared. In most human service programs, this is an impossible task. There are usually multiple benefits and it is remarkably good fortune if they are even identified. With the exception of employment and earnings outcomes, these benefits are rarely measured, or quantified in dollar terms. Who, for example, has developed a measure of the increased value of homemaking services resulting from rehabilitation and other services? What value should be placed on the psychic benefits of these programs? And this only touches on the problems of placing dollar values on many of the benefits of human service programs.

In consequence, one usually cannot conclude on the basis of a benefit-cost ratio, that a program is not worthwhile (since only part of the benefits are measured) or that one program is more advantageous than another, or that it is more desirable to serve one group rather than another.

We should be reminded of periodic efforts to calculate benefit-cost ratios for different groups of rehabilitation clients. For many reasons, such efforts are usually meaningless. Unfortunately, if people take them seriously, they can be extremely harmful. For example, one well-known study purported to show that the benefit-cost ratio for rehabilitating mentally retarded persons was lower than for rehabilitating other disabled persons. The obvious conclusion was that resources should be shifted away from mentally retarded clients in favor of other clients. Unfortunately, the study failed to take account of the fact that **most mentally retarded clients had only recently left the school system** and were usually teenagers. Not only were their earnings low, but so were the earnings of most other teenagers. However, as they grew older, their earnings would be expected to rise more rapidly than the earnings of older rehabilitants. The study, however, failed to take this into account and simply projected the earnings of all rehabilitants to rise at the same rate.

In the future, measures of the attainment of prescribed goals, such as the attainment of employment, the achievement of substantial wages, and the length of time on the job are likely to be more valuable tools than benefit-cost ratios in measuring the success of a program.

-- RONALD W. CONLEY

This is an interesting article by a highly regarded rehabilitation professional who has a national perspective on benefits and costs associated with disability programs. For the professional who is uninformed about economic terms, the introductory section of this manuscript provides helpful definitions. The majority of this paper contrasts several programs' benefit-cost data. Each of these programs show favorable benefit-cost values. However, it would have been helpful to review sample demonstration sheltered employment programs and adult day programs which focus on pre-employment (work adjustment) activity. I think until the figures are sharply contrasted it will be very hard for advocates to **galvanize bureaucrats and the political process for systems change.** I would hope this paper lays the groundwork for a step-by-step process of stimulating the current state bureaucratic establishments, such as Vocational Rehabilitation, Mental Health, Mental Retardation, etc., to reflect 1985 research and demonstration.

-- PAUL WEHMAN

The Hanks chapter provides both an informative and excellent overview of Cost-Effectiveness and Cost-Benefit evaluation approaches and their importance in improving decision-making and insuring continuing funding. His overview of such research in relation to five (5) ongoing transition programs provides adequate data to continue these efforts. A conclusion which should not be overlooked is that the movement should try to insure that program data can be collected and utilized objectively to facilitate future policy formation.

While the realities of the need for such numerical estimates of cost-effectiveness or related such data are a given and should not be overlooked, such findings should be utilized in a secondary way only since the risks inherent in such evaluations related to overlooking societal obligations to provide such program services.

The author notes that social problems are extensive and complex and the legislative response to these problems are bound by coalitions of interests oriented toward particular courses of action. The analysis provided is but one of numerous means we need to implement to help educate legislators and the general public about the benefits derived from politically suppoting transition-type services.

-- AMOS SALES

The Hanks paper provides an excellent background in cost benefit analysis and cost effectiveness. In fact, it provided this reader with **"every thing I ever wanted to know about benefit-cost analysis,** but didn't know enough to ask." Hanks treated the subject in a very thorough and comprehensive manner, but yet failed to take advantage of the material that he presented for the furtherance of transition for students with disabilities from school to work and independence.

Perhaps the aura of Mary Switzer is, for those of us in rehabilitation administration, our own handicapping condition. How frequently I have heard from a variety of rehabilitation practitioners the need for another leader like **Mary Switzer.** While we're waiting for an inciteful and charismatic leader, we sometimes fail to use our own abilities to make those decisions that will ultimately impact on the lives of persons with disabilities.

Hanks' excellent treatment of the need to utilize benefit cost analysis and cost effectiveness analysis for program coordination and policy reform begs the question ... why can't we, with this analytical information, be more prescriptive in calling for policy and program reform? The author suggests that we still have a great deal to learn about the economics of disability and the benefits and cost of transition programs. I suggest that if we wait to learn anymore, our newfound knowledge will merely illustrate our ignorance. British writer and social critic, Malcolm Muggerridge, once said:

"Accumulating knowledge is a form of avarice. It lends itself to another version of the Midas story, this time, of a man so avid for knowledge that everything he touches turns to facts. His faith becomes theology, his love becomes lechery, his wisdom becomes science, pursuing meaning he ignores truth."

It is time for more of us in rehabilitation to stand on that cost-benefit analysis data that we do have and not only call for policy makers to make change, but be directive as to what that change needs to be. Hanks' identification that political judgements are seldom made until hard figures are presented may be true some of the time, but most of the time the decisions are made in response to those loud voices that have both the hard figures and a well identified mission and purpose.

Paul Wehman, and the work of his associates at Virginia Commonwealth University, have succeed-ed in documenting the benefit-cost analysis and the cost-effectiveness of the research efforts. However, I beleive their success eminates more from their identification and articulation of what needs to occur in a successful transitional employment program.

Perhaps those of us who are in a position to see the need for transition and those who appreciate the statistical evidence that we have available should assume more of a Walter Mitty role in directing change within the disability service program. Dreaming dreams out loud may offer us the opportunity to act out those dreams in behalf of youth with disabilities.

-- MARVIN L. TOOMAN

The underlying premise of Hanks' presentation is that, given the wide range of disability programs in the United States and the duplication and overlap of programs, and the potential for economic, social, and personal waste, we should establish the appropriate mechanisms to utilize benefit-cost analysis to assist us in answering the questions of efficiency and equitability of our present and future work-oriented programs including transitional programs.

His paper has clearly presented an analysis of relative cost and benefits related to the outcomes specifically with regard to the transition to work of persons with disability, how these benefits and costs might be calculated and the present limitations of this process.

He makes a strong argument for the utilization of benefit-cost analysis as a valid means of developing more objective evidence to be weighed by policy makers in their deliberations and decision-making process. Hanks provided a well developed presentation in exploring the difficulties in estimating the costs of programs and the difficulty in estimating the benefits of programs. In spite of these difficulties, however, he contends that benefit-cost analysis will provide the most direct way to calculate program efficiency by measuring the dollar value of inputs against the dollar value of outputs of an activity.

The author provided an analysis of five of the newer transitional employment programs relative to their costs and benefits, and concluded the following:

A. These transitional employment programs would not necessarily cost less than traditional day programs and sheltered workshop programs.

B. They do compare favorable relative to an acceptable range of costs.

C. The anticipated advantage might lie in the monetary and non-monetary benefits that they yield.

I feel that this last observation requires a more in-depth analysis of the specifics of what constitutes these monetary and non-monetary benefits. Are they measurable?

Also, in examining the benefit-cost analysis, three perspectives were examined: (a) the participant, (b) the social aspects, and (c) the taxpayer.

It would seem appropriate if not absolutely necessary to include another perspective for consideration in the benefit-cost analysis; and that is, the impact both have, i.e., cost benefit, **on the businesses in which transition programs take place.** We may be drawing conclusions without entering an important ingredient into the equation -- business.

I do feel that this paper raises an extremely important and valid issue that will require in-depth consideration. The author points to the need to standardize the design of transition programs within the policy content of a set of principles. He has set forward for consideration ten principles which he feels if utilized should result in a greater impact on both policymakers and their decisions.

The issue of benefit-cost analysis raises an important question for consideration: How does one develop the data framework, tools, and mechanism to effectively utilize a benefit-cost analysis approach to the transition to work programs which are and will be operated? While implementation is the important question, I agree, however, that the more we are able to present supportable hard figures the better chance that the political judgements made by policy makers will be tempered.

-- CARL V. PULEO

Hanks has provided an excellent overview on economic considerations in transition programming. I agree with the application of benefit-cost techniques for the continuing development of transition program. However, efforts to develop expressions of political purposes to compete for scarce resources must proceed cautiously. Very often programs competing for these scarce resources feel that they must demonstrate that their unique delivery systems are superior to other methodology which might be applied to an entirely different population of disabled individuals.

I feel that a qualification must be made regarding the 250,000 to 300,000 who are believed to leave special education programs annually. The paper indicates that most of these individuals will need additional help beyond school in making the transition to work. I believe that many of these individuals, depending on the quality of their elementary and secondary programs, leave public school without any additional support. **Many others will**

require only short-term intervention to enable them to become assimilated in our communities. Some individuals leaving public schools will need ongoing support to be maintained in our communities. These individuals should not be preceived as lifelong rehabilitation clients, but rather as individuals who will be in the most normalized environment if support services can be maintained in our communities. This particular level of effort is less restrictive and less costly than the "institutionalization" alternative.

Another caution regarding the use of benefit-cost analysis to develop expressions of political purpose relates to the emphasis being placed on performance standards. The Job Training Partnership Act (JTPA) attempts to use certain standards to quantify program results. However, these standards often dictate client selection because many programs feel they must select the most likely candidates to meet performance standards. Client need, or selection of clients based on greatest need are being over-shadowed by the need of programs to meet performance standards to demonstrate satisfactory expressions of political purpose.

-- WILLIAM HALLORAN

SUMMARY OF RECOMMENDATIONS

The following is a summary of the recommendations and implications for action developed by the Switzer Scholars as they relate to the topics of Chapter Three and Four. (The recorder was Marita M. Danek).

1. **Recommendations/Implications that would enhance service delivery.**
   - A. That the coordination of programs be improved so that the system of services operates in a unified and consistent way.
     - a. Goals should be developed for the student with a disability, and not only for the programs involved.
     - b. Eligibility criteria must be uniform across programs.
     - c. A unified comprehensive service plan should be required for each individual.
   - B. Establish a comprehensive information system to determine which methods of providing services are the most effective.

2. **Recommendations/Implications for policy or program development.**
   - A. Public Law 94-142 has assigned primary responsibility for youth with disabilities to the schools. Unfortunately, vocational goals for students and the needed vocational services to meet those goals are a low priority in most public school systems. We recommend full and rapid implementation by the states of the Perkins Vocational Education Act of 1984 and its amendments to insure the delivery of vocational evaluation and vocational counseling services by qualified personnel, including rehabilitation counselors.
   - B. Transition programming for youth with disabilities must begin at an earlier age than is currently in practice. Since educational programs are presently designated as the lead agency, massive educational programming changes for youth with disabilities are needed, such as:
     1. Parent education and advocacy training.
     2. Pre-transitional programs beginning in elementary schools and continuing through high schools which will include:
        a. Implementation of recently mandated joint efforts of vocational education, special education and vocational rehabilitation.
        b. Structured programs which will include didactic and experiential components which orient and expose the youngsters with a disability to the world of work.
     3. Alternative educational experiences such as functional curricular programming for sub-groups of disabled youngsters who are no longer benefitting from traditional academic programs.
   - C. That programs be developed to provide disabled students with meaningful paid work opportunities while still in school. These work opportunities may begin as early as age 14 and are intended to give students with disabilities the same work experiences as other students and to instill positive attitudes toward work. Responsibility for developing these work experiences should be shared between the local vocational and special educational programs and in consultation with vocational rehabilitation.
   - D. Eliminate the emphasis on demonstrating inability to work as a condition for eligibility for income transfer and health care benefits. Applicants should only prove that they would have great difficulty in obtaining work because of a disability.
   - E. Assure that beneficiaries who return to work are improving their financial situation.

F. Allow disabled persons eligibility for SSI* or SSDI/CDB if their income falls below the break even points for these programs. Similarly, allow disabled persons eligibility for Medicaid and Medicare if they have a disability that makes it impossible to secure private coverage.

G. Develop methods for supporting community-based residential care for severely disabled persons in settings that are not medical or that require 24-hours-a-day oversight.

H. Develop methods and resources of providing Federal funds for transitional and supported work activities for severely disabled persons.

I. Reduce the severe restriction on the level of countable resources allowed to SSI beneficiaries in order to encourage savings..

3. Recommendations/Implications for training of staff, the general public:

A. That a national public information effort be established which will insure that parents, professionals and disabled children and adults are made fully aware of the capacity of and opportunity for persons to engage in substantial employment. This will create an expectation that disabled youngsters can and will enter into paid employment as adults and not depend upon public support.

B. That a definition of qualified personnel as noted in the Perkins Vocational Education Act and its amendments specify that such personnel have a Master's degree in vocational evaluation, school or rehabilitation counseling; relevant certification or licensure and a knowledge of disabling conditions and their vocational consequences.

4. Recommendations/Implications for needed research:

Additional research and program evaluation is needed to enhance understanding of the economics of transitional programming. Such research will help insure that resource allocation decisions are made on the basis of the benefit to the persons with a disability and economic efficiency rather than upon the desire of service providers to perpetuate themselves.

A. Benefit cost-analysis and cost-effectiveness analysis should be used by program administrators to improve and refine resource allocation decisions in transition programs.

B. The data collection and analysis involved in demonstration projects should be used and disseminated as a basis for structuring policy decisions on national, regional and local levels as it concerns transitional programs.

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* *SSI - Supplemental Security Income*
SSDI - Social Security Disability Income
CDB - Continuing Disability Benefits

Switzer
Scholar
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Chapter Five

Families in the Transition Process: Important Partners

By Barry L. Mendelsohn
and Jacqueline Z. Mendelsohn

With one child ready to go away to college, but right now concerned with renting a tuxedo for his prom, and another child more interested in dungeons and dragons on his computer than his homework, adolescence is in full force in my home. I love them both, but I worry more about my deaf son -- my hearing son will have to prove himself to be a success in the world -- my deaf son will have to prove himself and fight society's prejudices to be a success in the world. I am trying to raise him to be his own advocate. Last week I told him I was having dinner with the coordinator of his school program. He said "Say hi, and tell her we need another interpreter." I thought, "right on." This kid knows what is needed and will be able to ask for it -- I believe that that is a strong part of independent living skills. I expect both my children to have good, independent lives as adults. I just expect my deaf son to have to fight more for it.[1]
-- A parent

The concept of parent-professional partnerships in preparing disabled youths for entrance into the world of work is by no means a recent phenomenon. We have attended conferences for ten years where pledges of cooperation are made, signed in red ink, sealed, but rarely delivered. Everyone believes the cooperative model is the best but few are clear as to how to implement it. We believe that the reasons for the failure are complex, and not simply a matter of people being too busy or too insulated in their respective disciplines. We have had some success in "bridging the gaps" and will discuss our ventures in a later section of the paper.

The main body of our paper will focus on developmental dynamics in families with handicapped youths. We will seek out major stress periods, passages, and aspects of family life, regardless of the handicapping condition. We will center most of our attention on four transitional periods: diagnosis of the disability, the "latency" years, puberty, and late adolescence. The discussion will be illustrated with clinical vignettes, as we hope these personal stories will underline more clearly those factors which help us predict the success and failures in parenting a disabled child. Wherever possible, we will try and bring in relevant psychodynamic or biological models.

General Comments

The vast majority of parents with disabled children are themselves free of handicaps. Few may have had experience with anyone who has the same disability as their child. Parents often feel they are raising a "stranger," a child about whom they know very little. Most parents use their own parents as models for raising their children. Thus, when the child does not fit the norm, the parents have no immediate model to follow and are left to sort through the often conflicting advice offered by the diverse professionals who enter their lives, once a diagnosis is made. In addition, parents feel isolated from their peers, the parents of "normal" children.

Illustration: The mother of a 4-year-old blind, retarded boy finds it increasingly difficult to go to the park with her son. Watching the mothers with their sighted and verbal children leaves her cold and empty. She wonders if she will ever feel whole again.

The mother is particularly isolated and looks for companionship and validation from the husband. Marital strain often follows. Previously normal communication patterns are disturbed by the doubt, resentments and guilt feelings set off by this "alien being." Parents "forget how to laugh." Will they love this child when he/she grows to adulthood, and cannot do things the others can do? Will they be stuck with the child forever? Who will help them cope? There is nothing quite so vulnerable as a parent of a disabled child. Society has changed over the past few generations. We now find widespread acceptance of single parent families, working mothers, marriage and children at an older age; even a failed marriage and a divorce is now acceptable. However, a child who does not live up to society's expectations, or who fails his parents is not acceptable. Parents take the responsibility, the blame for the "failure." Most cannot separate themselves from their child's behavior or difficulties, or disability.

Parents will utilize different defenses to minimize the damages done by the assault on their ego. Regardless of the defenses employed, it is our contention that **residual** guilt and rage persist whether the parents are "responsible" for the handicapping condition or not. It really doesn't matter why a child is handicapped as far as parental **feelings** are concerned. For professionals to intervene successfully they need to understand that pockets of these two powerful emotions, guilt and rage, remain in even the most "well adjusted" parents, with the most "successful" disabled children, and even years from the diagnosis. Some of the common defenses employed are **reaction formation, over identification, sublimation,** and over-idealization. All grow out of partial or incomplete resolution of the grieving process, which will be elaborated shortly.

Reaction formation

This unconscious defense allows one to keep hostile and aggressive impulses submerged, utilizing the energy to function more positively with the object of the negative feelings. Often the effort is overstated.

Illustration: A mother of a severely impaired child devotes long hours to his care, to the exclusion of other duties and relationships. When others want "equal time," and confront the mother, her underlying anger comes out in statements of self-sacrifice and reproach.

Reaction formation protects the individual from directing hostility at the disabled child but does not allow for a resolution of underlying negative feelings. Rarely standing alone, it is often accompanied by denial and repression. It may also be coupled with overidentification with and idealization of the handicap.

Overidentification

This unconscious mechanism causes an attachment between the parent and child to take place. The attachment is not the same as we see in parent-child bonding, where the child directs loving feelings in response to nurturance from the parent. This attachment is not a healthy development regardless of the level of its intensity, as it is based on the handicap and not on the child. A parent may then "accept" the handicap and not the child. Further, parents who themselves feel incomplete or disabled may use the child's handicap to fill their emptiness. Overidentification should not be confused with advocacy for handicapped causes, or acquiring expertise in the handicap.

Professionals often complain that a parent is too involved, too outspoken, too abrasive. Sometimes they are sensing the parent's underlying hostility and unresolved grieving. Just as often they may be reading in pathology where it does not exist. In order to determine what is what, the professional might take an emphatic and involved stance, submerging his/her own reactive defensiveness, and get the data needed to make the "diagnosis." In this kind of situation, patience is truly its own reward.

Sublimation

This defense is defined as a mechanism in which the energy associated with unacceptable impulses or conflicted feelings is diverted into more acceptable or available channels.

Illustration: A middle aged father, subconsciously aware of waning love feelings toward his wife, devotes his non-working hours to his multiply disabled daughter, who is a young adult. His outspoken goal is to teach her many things and to prepare her for eventual emancipation. His unconscious motivation is to keep her with him always, a devotee of his loving ministrations.

Idealization

This defense is defined as a conscious or unconscious overestimation of another's attributes. With regards to handicaps, it is seen as a reaction to the disability where, to allay anxiety or to submerge negative feelings, the parent will ascribe specialness or supernatural meaning to the disability.

Illustration: A young couple, members of a fundamentalist church, learn that their toddler son is deaf. When encouraged to begin sign language in order to start putting language into the child, the couple smile and say, "that won't be necessary. Our son is a precious burden, a gift from God. Prayer, not sign language, is the answer."

This particular example shows the underlying ambivalence in the couple's position. Denying their grieving, they place their fate in God's hands, feeling, on the one hand, blessed to be given the responsibility to care for the disabled child, while, on the other, asking God to cure him of the affliction.

Idealization is common for all young couples, as they approach parenthood. Parents often see the expected child as a fulfillment of a childhood fantasy -- a demonstration to the adult world that we **can** accomplish something of worth. All couples experience the desire for the birthing of a perfect child. Part of the magic of childbirth for a young couple is the dream that a baby is a gift to the spouse, the living embodiment of their love for one another. When the infant is not perfect, the dream dies. The couple is faced with the reality of a disabled child. Grieving begins.

The Grieving Process

Grieving is a normal process when one has lost a significant dream.[1] The process is never completely resolved, and each stage proceeds at a pace determined by the internal makeup of the parents, and the nature of the support systems available. When confronted with loss (in this case the "death of perfection"), parents respond much like one does when mourning the actual death of a loved one. Obviously the emotions may be muted. The infant is alive. Yet most of the feelings will be there -- initial numbness and denial, followed by anxiety, perhaps panic. All parents will then experience depression and guilt, accompanied by periods of anger and protest. At some point, the acute process resolves, with the above emotions being expressed again and again as the parent struggles with the realities of the handicap as it touches the family, the school, the community, the working world.

This struggle may hamper the development of parent-child and parent-professional alliances, so vital to the transition of late adolescence and early adulthood. Most disabled people can achieve some degree of independence from family and caretakers. Obviously, some disabled children will achieve limited independence. Some will require supervision and continuous advisement; some will need physical assistance on a continuous basis; some will remain in institutional settings. A few may remain under the care of their parents, their adult lives essentially an extension of their childhood years. All too often the growth process is disrupted by unresolved grieving, incomplete acceptance of the handicap and its implications on functioning, faulty bonding between parent and child, or incongruent communication between the disabled youngster and other family members.

A parent who becomes fixated in the grieving process ("stuck" on denial, anger, or protest), comes into conflict with the child, spouse, and professional. We see counterproductive behaviors in the office and school, and we recognize the difficulty in helping a parent through the grief process, particularly when the anger and pain has persisted many years. Working through grief is an essential component of acceptance of the disability. Acceptance is necessary before alliances can be effectively set up and directed toward reachable goals. As professionals, we must recognize that parents are the essential ingredients to successful transition, regardless of the degree of disability, and it is our responsibility to build their confidence, dress their wounds, hear their complaints, strengthen their competent efforts, and guide them through the hard times of diagnosis, school life, adolescence, and beyond. For starters, we need to understand the grieving process and how people might behave at each stage.

Denial

"This doctor must be wrong -- I will go to another one and get a better answer." Denial is a parent's way of buying time to understand the diagnosis. Obviously some diagnoses are easier to dispute than others. Parents of children with hidden handicaps will generally shop around. All will put off dealing with the realities of the disabled child. Searches for miracle cures are common during this time. Later, denial of the implications of the handicap are particularly detrimental to the transition to adulthood.

Anxiety

Anxiety is best understood as coming in two phases. Acute anxiety, perhaps accompanied by somatic distress, confusion, and feelings of panic, may be experienced at the time of diagnosis. Later, anxiety is experienced when parents are unsure of how to manage their disabled child. Self-esteem may be diminished, as doubt creeps into the parenting process.

Depression

In the acute process, parents are bereaved. They mourn the loss of the perfect child. They may feel helpless. They may experience loss of appetite, sleep disturbance and preoccupied thoughts. Early in the child's development, we may see an immobilization of energies which interfere with communication and bonding. As the child develops and hits snags, the parents will re-experience aspects of the earlier depression. At these times, professionals may view the parent as having "given up." Without appropriate intervention, the parent may be paralyzed by the view of the future as an endless rerun of the present. Depression is one of the more "treatable" areas of the grieving process.

Anger

Anger is sparked by the clash between reality as we want it to be, and as it is. It is a venting of frustration, an escape of pure emotion. Anger often positively motivates action. It is generally demonstrated by outbursts at the child, at oneself, at one's spouse, or at the professionals throughout the child's early life. Anger may manifest itself as overprotectiveness of the child, or, in the other extreme, a neglect of the child and the disability. Angry parents are seen by professionals as "carrying a chip on their shoulder" and being extremely difficult to work with. Anger often conceals the guilt associated with not doing enough for the child and others in the family.

Guilt

In small doses, guilt is a normal and expected emotion. It may even fuel certain kinds of positive behaviors, by sparking the superego. Guilt commonly accompanies depression at the time of diagnosis. High levels of guilt and blame are found in genetically related disabilities. "Deafness runs in my wife's family. It's her fault." As time passes, pathological guilt undermines acceptance of the disability. Parents may be unable to "roll with it." They may continue to seek self-critical answers to the question, "why me?" We often hear parents preface a comment with, **if I only...** (my child would have been all right). They strive for some idealized notion of what a parent should be, but, having remained immobilized by guilt, even the most mundane and routine decisions become obstacles. As with depression and anxiety, untreated guilt will cause the parent to lose self-esteem, feel unworthy, and lose faith in his/her abilities (competence).

Role of the Professional

Professionals are very important people to parents immobilized in the grief process, particularly in the early stages, and, in many cases, even before diagnosis is made. The right intervention by the appropriate professional can steer a new course for a parent in need.

Stereotypes may arise in the minds of professionals which cause an imbalance in the working alliance and slow resolution of the grief process. We have pinpointed two common stereotypes, the "hysterical mother" and the "absent father."

Illustration: An irate mother storms into the principal's office, after being placated (but not listened to) by her child's teacher. Feeling demeaned by the system, she pushes too hard in her effort to make her feelings and ideas known.

Illustration: A father, whose hands are calloused by hard physical labor, slips off to watch Monday Night Football, while mother practices sign language with her son. "It doesn't matter," he says (a little sadly), "My wife interprets for me. She's much better at it."

Mothers often do become hysterical after years of being pushed aside, or listened to with little or no respect by professionals. Fathers become isolated when all information is given to mothers, and mothers become more competent in areas concerning the disability. Fathers feel themselves falling farther and farther behind. Siblings are forgotten by overly committed parents who trade in regular living patterns for one where the disability reigns.

Trigger Points

Throughout the life of a disabled child there are "trigger points" which cause parents to re-experience different emotions connected to the grieving process. As professionals, we need to be aware of these periods in the life cycle of the family. We will focus on adolescence as it propels the handicapped youth toward eventual emancipation. We must comment on the earlier stages as well, for their successful completion provides the foundation for later successes in the transition period. Factors influencing this "final completion" include the degree of resolution of early and continued grieving, the timeliness and relevance of professional intervention, the acceptance by the family of the implications of the particular condition and a realistic attitude about the potential of the disabled son or daughter. The "bottom line" issue is whether the family and relevant professionals, understanding these factors, can form effective alliances that will smooth the transition process.

Let us start our journey through the life cycle with a look at the earlier stages, the prediagnostic phase, the diagnostic and post-diagnostic period, entry into school and the elementary years.

Pre-Diagnostic Phase

Before a diagnosis is made confirming a disability in an infant or child, the parents may have experienced months of uncertainty and undefined stress. Hidden handicaps (deafness, minimal brain disorders, mild retardation) may go undiagnosed for months or years. The parent may suspect instinctively that the child is not "normal" and turn to other family members or professionals who may miss the diagnosis. During this period of time parents may feel incompetent and unworthy. Spousal communication may break down due to feelings of guilt, anger and fear. Other children in the family may be neglected during this time as the parent seeks answers to the questions about this child. Living with the unknown profoundly stresses the family. In defense, parents become openly hostile toward professionals. The strategy for the professional is to be attentive and emphatic, remaining open to consultation with peers. A full diagnostic workup is essential. We might add that if a good bond is made between a parent and professional, that professional should remain a part of the team indefinitely. These early bondings are invaluable later.

The Diagnosis Crisis

When the child is diagnosed as handicapped, or disabled, the parents will enter a crisis period which consists of grieving, (mourning the loss of their dream) and confusion. This is a time when support services are crucial, when parents need professionals who are knowledgeable about the disability, about family needs, and specifically about the mourning process.

Parents often find themselves making critical decisions about their child's life at a time when they are unprepared, or still incapacitated by grief. For example, at the time of diagnosis, parents are asked to make choices about school programs, prostheses, communication systems, occupational therapy, and speech training. As time passes and families become accustomed to having a disabled child in the family and in the house, the confusion and anxiety will diminish and a "normal" living pattern will be established.

The School Years

When the child enters school for the first time, the parents are reminded that their child is "Special Education." The first day of school will be filled with meetings, stacks of special papers, bus schedules, speech classes, parent meetings, and IEP meetings. The parent may be overwhelmed by the responsibility, by feelings of inadequacy. These feelings may trigger depression, anger, or guilt.

The transition from home to school often comes at a younger age for the disabled child, thanks to laws providing early access to the education system. Depending on the handicapping condition and the time of diagnosis (and modified by state and local statutes and practices), disabled children can be receiving services shortly after birth. Professionals become "part of the family" from the beginning. School personnel are obviously the major participants during the elementary years, unless the child requires frequent hospitalization or medical and surgical interventions. The forging of strong parent-teacher alliances is mutually beneficial. Problematic behaviors are better understood, and distress signals picked up at an earlier time, before the behaviors become irreversible, or the emotional distress becomes chronic. School staff can help parents understand cognitive development and gains in learning. Social milestones are often reached in school where parents cannot experience them. Conversely, major events are occuring in the family -- job changes, separations and losses, complex or subtle "ecological" shifts, which may be only partially understood or completely missed by the disabled youngster (How many disabled children know what their parents do for a living?). Teachers can help the disabled student understand family shifts and strains, and bring valuable information to the attention of the parents (without, hopefully, embarrassing the child) which will result in the child's feeling a more vital connection to the energy flow of the family.

For the handicapped youngster, the elementary and pre-adolescent years should be a time for acquisition of knowledge and experiences where the limit is set only by the youth's capabilities. Unfortunately, many snares remain in the school and family systems. Parents may expect too much or too little of the disabled youngster. They may have unrealistic notions about the handicapping conditions and its implications in learning and behavior. They may leave the rearing process to surrogates or sibs, or neglect and abuse the child. They may belittle, humiliate, and condemn, or, conversely, overcompliment, or cater to regresssive behaviors in the child. Schools may hamper learning by inappropriate or "noncategorical" placements. Students may be given "social promotions," cutting them off from basic areas of knowledge, now left behind. There is little time in academe for programs geared toward emotional development and social skills enhancement (how to listen, to share, to resolve conflict, etc.). A teacher may miss the opportunity for a disabled student to obtain a timely consultation from an allied professional (special services, mental health, etc.) by ignoring symptoms or by being ignorant of their meaning. Occasionally, we see blatantly pathological interactions between parents and school personnel, where sabotage and scapegoating replace sharing as the **modus operandi.** Open warfare is uncommon. Public law 94-142 has provided for a continuous process of integrating parental involvement in the educational program, and disagreements are resolvable through a clear-cut review and grievance system. But the process is only as good as its component parts allow it to be. Apathetic teachers and parents make the system dispirited, repetitive, and nonproductive.

It is our contention that the years between diagnosis and adolescence are crucial. We must not see them as uneventful or as "pre-climactic" to the hustle and bustle of adolescence.

Cognitive Development

With adolescence comes the "age of formal operations"[3] or prepositional thinking.[4] These new mental constructions allow for higher levels of abstraction and a broader view of the world. Such changes are necessary to develop the mental attitude which allows for adolescent adjustment to the important worlds of school and peer group. At the same time, these cognitive developments can create problems for the disabled adolescent and the family. Children, once content with their adjustment *vis-a-vis* others' reactions to their disability, may now become depressed, anxious, and angry when dealing with the outside world.

Illustration: A thirteen year old multiply handicapped girl with active and sensitive parents suddenly becomes depressed and defiant. Previously, she compensated for her physical impairments by developing a winning personality. She was outgoing, witty, and entertaining. Now she looks at her disfiguring birth defects with growing awareness -- with the heart and mind of a peer-conscious adolescent.

Elkind[5] talks about the development of three cognitive abilities which may cause problems for the handicapped teenager. First is the capacity to think about what other people think (the "imaginary audience"). This new conceptual ability leads to heightened self-awareness which may lead to depression and withdrawal, as he/she comes to grips with the reality of the handicap and the limitations it imposes.

A second ability is the development of the "personal fable," an elaboration of earlier egocentric beliefs. Thoughts of invincibility and uniqueness often beset the disabled adolescent. Any endocrinologist will have several cases of young diabetics who go off their diets or "forget" their insulin shots during adolescence.

Illustration: A fourteen year old deaf patient who had dutifully worn his hearing aids, discards them and awaits the healing hand of divine intervention. Always a regular church-goer throughout his childhood, he had concretely accepted doctrinal statements. Now, having developed a higher level of "understanding," he incorporated earlier observed information in a new way, and awaited the intervention promised him.

The third mental construction described by Elkind is that of "strategic manipulation" or the ability to change rules for ulterior motives. Preadolescent children are characteristically rigid in their interpretation of rules. There is a right way and a wrong way, period. Adolescents, by dint of cognitive maturation, may shift rules, depending on underlying motivations. The handicapped youngster, once aware of strategic manipulation, may struggle harder with authority figures who are responsible for his/her health care and welfare. The empathic doctor may become someone who is just being nice to force compliance in the health program. Parents may be seen as manipulators, and the teenager may, in turn, manipulate.

The cognitive changes seen in adolescents are enough to befuddle parents and create family distress, and yet cognition is only one area of change and development. The family must also deal with the physical and social revolutions taking place. In the normal adolescent, the turmoil can provoke tremendous family upheaval. What about the disabled adolescent? In our practice, working with families with hearing handicapped children, we have found that the better the communication between parents and deaf child, the more likely the young teenager will act like his hearing counterpart, and go through the rebellious stage at the expected time.

The less informed, more overprotected deaf children are delayed in their adolescent milestones. Things seem calmer in early adolescence and the real turmoil begins at the next transition period. Thus, the hearing handicapped youngster with no other disabilities more closely resembles the multiply handicapped or physical limited young person if he/she is language and communication deprived. With the above in mind, what are the implications for parental intervention?

We have learned that caring for handicapped children requires patience, empathic listening, and regard for the child's opinions and needs (mothering, not smothering). We know that deaf children whose parents communicate in depth and negotiate rather than dictate act more responsibly and independently as teenagers.[6] Once a disabled youngster develops the cognitive skills described above, parental intervention must follow suit, by making such appropriate adjustments as cutting back on demand statements and "take-over" behaviors, and allowing the fledgling adolescent to make mistakes, as long as he/she is not endangering life or dismantling the moral code of the family. The parent must allow for distance to develop between himself/herself and the disabled youngster. We are not speaking of an aloofness or non-caring. We are talking about boundaries. The young adolescent needs room to try things out. Certainly we must protect all our children from potentially life-threatening acts, but that leaves a lot of room for trial and error. It is not particularly helpful to meet the impulsive statements or behaviors of the disabled teen with rapid-fire condemnations or steel-trap mentality, or derogatory statements bent on shaming or humiliating. Patience, thoughtfulness, trust, willingness to endure pain and anxiety are all characteristics that will show the disabled teenager that he/she has the room to develop strategies for adjusting to new feelings and body realities. It shows the teen that there is time for error -- a second chance. Few teenagers see this distancing as abandonment. In fact, most will rebel strongly to the overclose attentions of a parent.

Illustration: A 14-year-old physically handicapped girl, normal intelligence with learning disabilities regresses in toileting skills when her highly motivated and over-involved mother introduces a demanding, supervised home study program to bring her daughter to grade level. Marital discord rapidly accelerates as father feels excluded and is chastised as uncaring when he tries to intervene.

Adolescent rebellion amongst the disabled can take many forms, depending on the limitations imposed by the handicapping conditions. Regression is common if acting out is an unavailable pathway. Depression and withdrawal are often seen and may need professional intervention. Regressive behavior will often have the undesirable effect of bringing forth more controlling parental behaviors, reenforcing infantile behaviors. The disabled adolescent feels increasingly incompetent and the already fragile self-esteem system plummets.

Brandon[7] defines self-esteem as having two components -- competency and self-worth. A teenager's self-worth is measured by his/her sense of value as a person, within the contexts of the school, home, and most importantly, peer group. One's sense of value is directly proportional to the degree of connection with the other members of a particular milieu, and one's "place" or status in the milieu.

A person feels valued when he/she is heard, seen, recognized, listened to, believed, and so on (you get the idea). A disabled teenager is less likely to feel demeaned by the handicap if others in the milieu deal with it in an above-board and objective manner. For example, most non-disabled people get over their fear of a disability when they become familiar with it. Often, people will respond negatively or withdraw because they don't want to appear stupid, naive, or incompetent. As professionals, we must help the non-disabled feel less disabled when confronted by the disabled. Of particular significance to this issue is the development of one's place in the family system. An overly indulged or forgotten teenager will develop a skewed sense of value, carrying another disability into the transitional years.

Competency refers to actual performance. For the handicapped adolescent, we must adjust our concept of competency. Physical and intellectual deficits must be realistically appraised before valid expectations can be set. Once parents have a good understanding of the deficits, they must be careful not to overcompensate or to overdo for the teenager. Most often, parents err in the direction of underestimating the disabled teen's abilities. Our responsibility as professionals is to be as clear as we can about the teenager's capabilities, through exhaustive history taking and testing, and to encourage parents by demonstrating the areas of strength available to their disabled youngster. We need to teach parents to reenforce the strengths and not "play to" the weaknesses. The disabled adolescent needs to be held responsible for his/her actions. We do the disabled adolescent a serious disservice if we dismiss aberrant behavior not a function of the handicapping condition. It does not take long to develop the attitude that "I am disabled, and go by different rules. The world owes me a living."

Illustration: A deaf teenager is brought before a judge for stealing. His legal rights are upheld. An interpreter and attorney are present. He understands the nature of the charge and is aware of the proceedings at all times. He is released to his parents with a warning, because of his disability. No probation or penalty is assessed.

Self-worth for all adolescents is primarily a function of their success in developing a peer group. The reality of being established as an accepted member of the group (regardless of its makeup, belief system, or behavior) is a major component of the adolescent's acceptance of his/her handicap. Failure to develop meaningful peer alliances in the early and mid teen years substantially inhibits the timely process of emancipation in early adulthood. The knowledge gained by the disabled teenager as he joins with others like himself/herself (or is accepted into "normal" circles) is as important as the academic skills achieved in the classroom. Interestingly, it is more often social deficiencies that impede the emancipation phase, rather than academic shortcomings.

Teenagers develop many new skills when they choose a social milieu. They undergo a step-wise process that requires an initial survey of available groups, an assessment of reactions of others, a search for common values, a monitoring of personal reactions and family attitudes, a solidification of personal identity within the social milieu, and a development of leadership abilities (see figure 1). This process helps to further one's acceptance of the disability and gives valuable feedback as to the scope of the disability *vis-a-vis* social functioning.

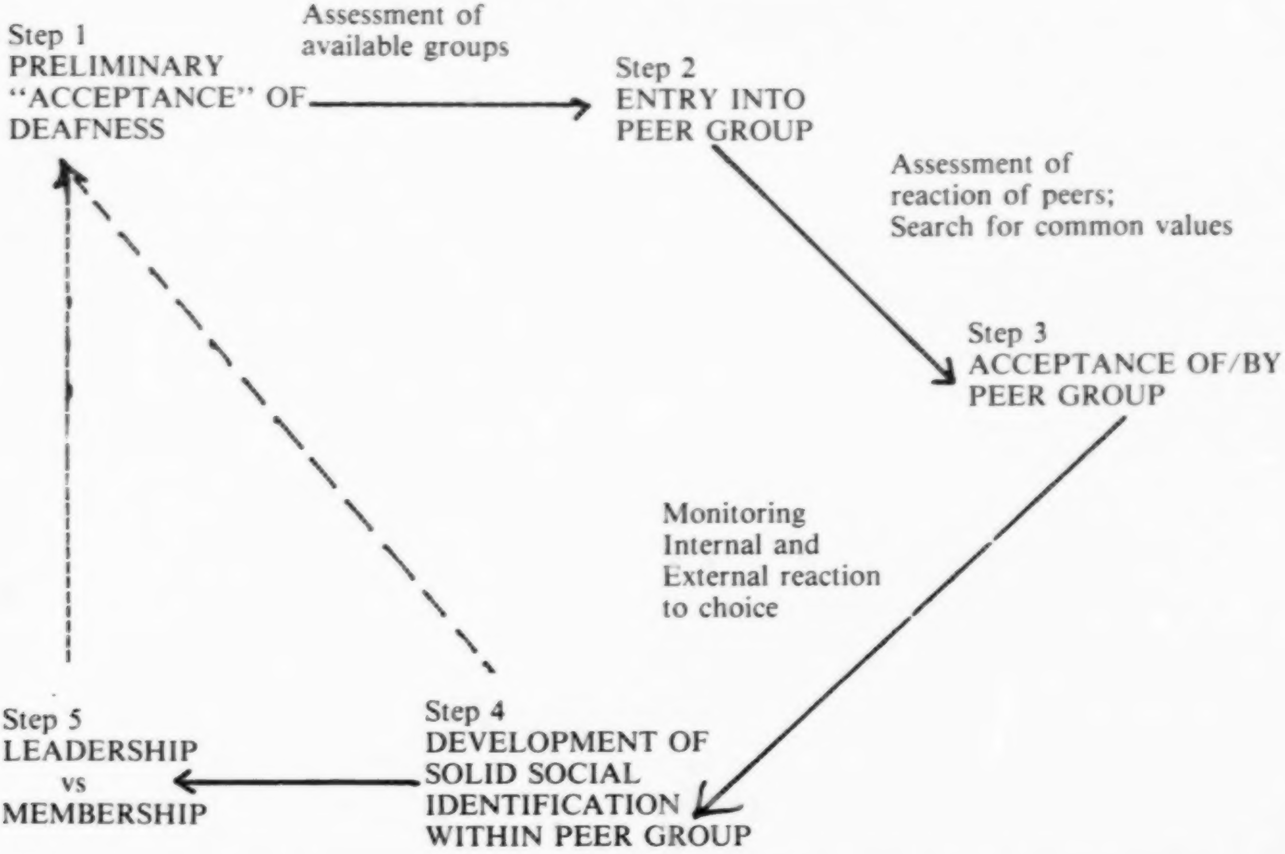
Parental acceptance and encouragement of the peer group is crucial for the disabled adolescent. Although many disabled youths need closer supervision and consistent help in following through with social contacts, the strategy for parental involvement should be "laissez-faire" -- give the teenager room to try, whatever the outcome. The kids need the chance to adjust their goals or their approach to seeking acceptance. If they consistently fail, then they may need counseling or advisement, so that they may readjust their sights or change their approach.

The development of a flexible attitude is a core feature of parent-adolescent alliances. As we have noted previously, parents who have mastered the grieving process and have established a realistic attitude about the disability are more likely to be flexible in their approach to the teenager.

Parent-Professional Alliances

During the developmental years, professionals help to determine educational and medical strategies, provide direct services to disabled youths, and periodically assess potential and progress. Just as families are in a constant dynamic flow, so must

A Model Of Social Identity


Step 1
PRELIMINARY "ACCEPTANCE" OF DEAFNESS
Assessment of available groups
Step 2
ENTRY INTO PEER GROUP
Assessment of reaction of peers; Search for common values
Step 3
ACCEPTANCE OF/BY PEER GROUP
Monitoring Internal and External reaction to choice
Step 4
DEVELOPMENT OF SOLID SOCIAL IDENTIFICATION WITHIN PEER GROUP
Step 5
LEADERSHIP vs MEMBERSHIP

professionals be ready to shift gears, to establish new goals, and to call for reenforcements when needed. In our work with parents, we have found that successful alliances are possible, are generally desired, and are built on a foundation of mutual respect, an open attitude, availability, and perseverance.

Mutual respect: Parents are experts, too. They have had years of experience. Listen to them. Build on their ideas. Don't patronize or placate. Deal honestly. If you don't know something, say so. Be warm but not overly "chummy."

Open Attitude: Be ready to learn something new or to try something risky. Challenge and be challenged.

Availability: Answer phone calls the same day. Be available for conferences. Use time together wisely.

Perseverance: Longstanding parent-professional relationships make the best transitional alliances. Professionals who have a dynamic understanding of the disabled person and the family make better judgments and offer more realistic advice. It is never too early to add the rehabilitation counselor or vocational specialist to the team.

As the adolescent nears completion of the educational phase, the team becomes increasingly more important. All too often, parents and vocational specialists work separately. Inadvertently, they may work at cross purposes.

Illustration: A 22-year-old deaf man lives with his parents. He visits his vocational rehabilitation counselor in hopes of finding a job. The counselor and the parents have not met. Each view the young man from a different set of experiences. The parents disparage the counselor's vocational choices. The counselor sees the parents' aspirations as overly ambitious. The young man is caught in the middle.

Many hours are wasted when parents and professionals fail to team up in face of this complex and challenging task. Professionals put themselves at a terrible disadvantage if they try and place a handicapped young adult in the work force with only pieces of the picture at their disposal.

We will now offer our blueprint for the transitional period:

1. Start early. Whenever possible, become acquainted with the family when the client is in his/her teens. If that is not possible, review the social, medical, and educational history as extensively as possible. Talk to parents, teachers, sibs, and so on to get a deeper understanding of the potentials of the client. If the client's behavior is puzzling, or the diagnosis obscure, ask for additional evaluations. Tell other professionals what you want, or need to know.
2. See the client in real situations. Visit the classroom. Watch social interactions. Have the family meet as a unit with you. Visit the home.
3. Set up vocational counseling groups in the schools. Listen to what kids have to say about their interests, their fears. Encourage kids to talk about how their handicaps will affect their ability to work, and to live independently. (You may want to team with the school psychologist).
4. Involve disabled adults. There is no better model for success than a success story in the flesh. Bring disabled adults together with disabled adolescents. Use adults as consultants to the family. Enlist their aid in setting general strategies in the agency and in the schools.

Coleman[4] (1974) suggests another model that deserves attention. He takes the parent-professional alliance concept one better, talking about larger efforts involving schools and the community, all collaborating to create "multiple environments" in which the disabled adolescent can practice a variety of roles, in preparation for entry into the world of work. Much recent work has focused on program models. The need now is to bring this information to the attention of the appropriate workers so that clients can find the programs. Granted, new funds would be needed, or perhaps old funds redistributed. Inasmuch as we're espousing an ecumenical approach, some aspects of the rehabilitation process would change as well, requiring additional training, shifts in personnel, etc. Our contention is that the short-run disruptions would be well compensated for by improvements in outcome and by coordination of services. Worker burnout would decrease as other resources become available, and as more realistic goals were established.

No parent-professional alliance would be complete without the availability of support groups. We have ample experience with self-help groups as they relate to substance abusers. We know that ex-drug and ex-alcohol addicts are effective counselors for people in the transitional phase from addiction to sobriety. Similarly, parents are effective and empathic counselors for one another, particularly during times of change (the "trigger points" we mentioned earlier). In addition to the support group, peer-oriented working groups are also very effective. For example, parents of disabled junior high school students might band together to canvas community resources, meet with handicapped adults, and begin to introduce their children to the outside world. Small groups of handicapped youngsters could go on field trips to visit parents in the working place, to learn firsthand what work is all about.

Our ultimate goal? We hope to see kids who feel that their growth toward adulthood is a shared experience, where their potential is understood and encouraged by parents, teachers, counselors, and other practitioners. We recognize that many disabled young adults will reach a limited degree of independence, but let that level be the top of their ability, the best of their effort. We seek a time when parents and professionals can say, "we knew what we had to do; we knew what we had to work with; lots of good people helped along the way; and we're proud of what we've accomplished." ☐

Footnotes

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5. Elkind, D. "Cognitive Development and Adolescent Disabilities," in **Journal of Adolescent Health Care**, Vol. 6 No. 2, March, 1985.
6. Schlesinger, H. and Acree, M. "The Antecedents of Achievement and Adjustment: A Longitudinal Study of Deaf Children," in **The Habilitation and Rehabilitation of Deaf Adolescents**, Eds. Anderson and Watson, National Gallery of Gallaudet College (Publ.), 1984.
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EXCERPTS OF REVIEWS AND COMMENTS

The following are excerpts of reviews, comments and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as it relates to the content of Chapter Five by Barry Mendelsohn and Jacqueline Mendelsohn.

The authors' analysis reflect clearly an already recognizable need for parent training and education. What is brought to the forefront, however, is the **need for intervention** and education/training to occur very early on -- even as early as the point in which disability **has been diagnosed.** To what extent has medical/psychological intervention at the onset of disability recognition been accomplished, and at what success level? Recent contacts with parents and parent leaders reveal that many are still experiencing parental complexities dealing with depression, guilt, anger, and general dissatisfaction because the service systems are not moving as quickly or as efficiently as they would desire. Much of the parental frustration is caused by lack of awareness and knowledge of the service delivery systems programs, resources, capability and constraints.

-- MIRIAM E. WALKER

I was very pleased to see this topic invited to the seminar series. I am writing this review not only as a professional, but as a parent of a seriously health impaired preschooler. I was most pleased with the parent professional alliance discussed in the paper; in fact, this section could have been expanded significantly. I think the section on the Role of the Professional, might have been expanded to include the roles and actions of different professionals in the early age, school-age, and transition-age period. Also, much more on the notion of parent-to-parent (see counseling) and its role in the process would have been useful.

-- PAUL WEHMAN

Mendelsohns' discussion of families in the transition process confirms that they are warm caring parents of a disabled child. As important as that consideration is within this paper, it should also be noted that they are very articulate and competent as professionals seeking to smooth the transition process. This combined perspective offers the reader the opportunity to look inside the life experiences of parents with children who are disabled.

The feelings and emotions of both parents and children with disabilities are vividly described through vignettes distributed throughout the paper. One can quickly conclude that parents of children with disabilities experience many of the same situations and events as the parents of children **without disabilities.** However, they also have a range of experiences that are **unique in comparison** to their peers, frequently taking on dimensions that challenge the patience and understanding of the parent and professional alike.

I'm reminded of Harris' Transactional Analysis of the 1960's, as the Mendelsohns discuss the movement of a child with a disability into adolescence. The occasioned rebellion of an adolescent with a disability forces the parent to select between the roles of parents, adult, and child. The authors confirm that the role of the adolescent and the subsequent line of communication can be directly influenced by the role of the parents. Further, it is important for the professional to analyze and gain an appreciation for the relationship that exists between the parent and their child with a disability prior to the development and the delivery of education or rehabilitation services.

In total, the Mendelsohn paper has the potential of becoming **a primary resource for parent support/advocacy groups, pre-service training programs for student seeking to serve persons with disabilities, and education and rehabilitation professionals serving within the transitional process.** Through this paper, the dynamics of the family assume their rightful role within the service delivery system for youth with disabilities.

-- MARVIN L. TOOMAN

The Mendelsohns' paper highlights very critical knowledge needed for professionals to be able to effectively work with "Families in the Transition Process." The insights provided particularly those in relation to Parent-Professional Alliances should be required reading within all rehabilitation and related professional training programs and of all current practitioners.

Public agencies and institutions providing educational or rehabilitation services to individuals with disability in practice, ignore the singular impact of the family of the student and/or client they are attempting to serve. This is particularly true within the State-Federal Vocational Rehabilitation Program where the diagnosis-remediation process of service delivery is often completed, at least in terms of counselor-client contact, without family involvement. Research has existed for some time to indicate that the single most important factor in rehabilitation success is that of **positive family support.** With this awareness and insight provided by the Mendelsohns, professional practitioners could modify current practice, develop family-professional alliances, and greatly enhance the quality and outcome potential of their services.

-- AMOS SALES

The authors have very clearly laid out a blueprint for success in the mutual assistance of preparing youth with disabilities for entrance into the world of work.

An underlying theme of this paper is the focus on communication and involvement of the individual with a disability in the developmental plans and transition process.

The authors emphasized the positive concept of bonding, the first between parent and child, parent and professional, child/youth and professoionals that is necessary for appropriate growth and transition through the "trigger" points in the developmental phases through which the child/youth moves toward the world of work.

The important role of the appropriate professional(s) whatever their discipline has been well presented. The emphasis on parent-professional alliances might be expanded to include adolescent with a disability, parent, professional alliances.

The blueprint for involvement of the professional in the transitional period rightly begins with "start early." It will be well worth the time to develop specific strategies around each point raised in the blueprint. Once a strategy is developed, the need for policy change, additional resources, redirection of existing resources, professional training, development of new linkages and alignments, etc. should be addressed.

An additional professional involvement within the blueprint structure is representation from the business community. If an ultimate outcome in this transition process is work, then we must involve appropriate business professionals early on.

The paper lifts up a strong model of empathy, mutual respect, open attitude, availability, and perserverence that combined with knowledgable experience and commitment, can make the transition process healthy and goal directed.

-- CARL V. PULEO

The President's Committee on Employment of the Handicapped has taken the first step to respond totally to the Mendelsohns' suggestions in this transition process paper. We only need to take the **Pilot Programs Concepts** that are developing and enhance them for all disabled students and we have a program in place. Now, that is understating for certain what it would take to put such a program in place. But, nonetheless, the ideas are already under development for the more perfect transition process.

Frankly, I don't know why business and industry, government, school systems, rehabilitation and counseling, and voluntary agencies don't take this "bull by the horn" and do it for all high school students. In this country we need to develop proper attitudes for how all students make the transition from an overprotected education environment to a very autocratic living process -- work. Most people need to work to eat. Unfortunately, because of our social evolution, that is not a statement that describes all people.

The Mendelsohns have described a transition process from puberty on. It develops proper attitudes on the part of all participants in the process and it builds individual self-esteem. Self worth is very simply being a person unto yourself -- given proper respect and opportunity to be yourself.

High school vocational readiness revolves around one thing I believe -- testing people to determine what they can be expected to do and trying to present ideas on how to reach these individual goals. Unfortunately, the school system has never tried to involve those that will employ people in the process of discovery to as great an extent as we need to be involved. Again, this is an area only addressed by "loving, knowing" individuals who manage to develop meaningful and successful programs toward transitioning youth to the job market.

The concepts the Mendelsohns are discussing can certainly be achieved; but it will take communities with an enormous community cooperation. It puts the burden and responsibility where social burdens ought to be -- closest to home.

In the model program we build self esteem and proper values, focus on experiential learning give role models and focus on life opportunity and expectancy. We involve the student, the parent-home, the school, the rehabilitation agency, the government agencies, local people who voluntarily act as role models, and business and industry. We will end up with independent workers who accomplish dreams in reality.

-- ELIZABETH DEMPSEY

This paper presents a concise overview of developmental dynamics in families with disabled youth. The defenses of reaction formation, over-identification, sublimation and over-idealization and the residual guilt and rage are elaborated. The grieving process including denial, anxiety depression, anger and guilt often immobilize the parent. The role of the professional is stressed during the lifecycle and transition process and remains part of the team indefinitely. Unfortunately, this does not occur very often. The statement made "parents left to sort through the often conflicting advise offered by the diverse professionals who enter their lives" indicates that we as professionals need to have a consistency of information for the parent.

Some Implications for Training

1. Continuing need for ongoing training of all human service workers, including physicians, nurses, teachers, from birth to independence regarding the grieving process, anger, and the acceptance of disability.

2. Continuing need for refresher training for all groups of service providers.

3. The need to incorporate these ideas in text books as child adolescence development/psychology. If a chapter on disability and how it impacts development could provide for more acceptance by a society as , for example, early childhood illustrations now show racial minorities, have editors been encouraged to show children using wheelchairs, sign language, etc.?

4. Special education curriculum to include how to work with parents, other professionals.

-- FLORENCE R. CURNUTT

This was an excellent and enjoyable paper. I would wonder about the feasibility of the assertion that a professional should remain as part of the treatment team indefinitely if a good bonding is made between a parent and the professional. I don't question that it would be desirable to do so, but wonder if this is a meaningful goal given the high turnover among professionals, and the long-term needs of disabled children.

I failed to see any discussion in the paper of a question that always leaves me perplexed. What is the role and what are the **rights of families** when their severely disabled children become adults? Under what conditions, if any, should professionals and the courts act counter to the wishes of the families of adult disabled persons? For example, is it desirable to overrule parents who wish to maintain their adult disabled child at home when the best interest of the disabled person would be met by placing him or her in a community residence or even in his or her own apartment? What of the parent who opposes any effort to obtain a job for their adult child, perhaps because they are being overprotective, or perhaps because they fear the loss of secure Federal benefits?

-- RONALD W. CONLEY

SUMMARY OF RECOMMENDATIONS

The following is a summary of the recommendations and implications for action developed by the Switzer Scholars as they relate to the topics of Chapter Five. (The recorder was William D. Halloran).

1. **Recommendations/Implications that would enhance service delivery.**
   - A. The family must participate in all aspects of transitional planning and be involved in the decision-making process. Transition planning should start at the time the individual enters school, and adult service providers should be available to define their role in transition at the earliest possible time.
   - B. Students leaving public schools are often placed in a second priority status for community programs and services behind individuals leaving state institutions and/or under the care and custody of state agencies. Therefore, it is recommended that standards for community based services established for the deinstitutionalized population should apply to similarly handicapped individuals exiting public schools.

2. **Recommendations/Implications for policy or program development.**
   - A. The "zero reject" mandate in public education must be exanpded to adult services.
   - B. Continued program and service needs anticipated for students exiting or aging out of public schools should be identified at least two years before they exit. These anticipated service needs should be formally transmitted to adult service agencies and be reflected in their various planning documents.
   - C. Families will not assume case management responsibilities for family members, but must be involved in the decision-making process.
   - D. Implement policy directives to insure that parent-professional cooperation practices are implemented within educational settings, the State-Federal Cooperative Program, and the Social Service Programs.
   - E. Identify Vocational Rehabilitation (VR) CAP (Client Assistance Program) program as the consultive body within VR to initiate models and linkages needed to educated parents regarding VR services early in the education process.
   - F. Include a parent/consumer on the statewide Rehabilitation Advisory Committee.
   - G. Every state government should establish a distinct operational coordinating mechanism such as a cabinet council, to assure optimim integration of the service continuum, (from school to work, further training, etc.).

3. **Recommendations/Implications for training of staff, the general public, etc.**
   - A. Courses on the psychology or family dynamics, development of the disabled child, and parent-professional relationships, should be incorporated in all training programs for human service providers.
     1. Inservice courses on parent-professional partnerships should be provided for human service providers.
   - B. Training for parents concerning available adult services: including knowledge of programs and services, advocacy and independent living skills should be given by adult service providers.
   - C. Educational programs and adult service providers should implement public education efforts focusing on greater public awareness and sensitivity to individuals with disabilities as well as the services available to them.
   - D. Parenting classes for parents of children with disabilities be established and encouraged during the early childhood years.
   - E. The adult disabled community should be recognized and utilized as a primary resource in the transitional counseling process.
   - F. Attitudinal Awareness Training systems such as "Windmills" should be provided for parents to help them confront emotions about employability of their children with disabilities.
   - G. Training for families of disadvantaged and rural disabled children should capitalize on non-academic programs such as "New Life" and "Agricultural Extension Service."

4. **Recommendations/Implications for needed research.**
   - A. Priority for federal research support should be established which would create valid and reliable data in the area of community integration of severely disabled persons.
   - B. Priority for federal research support should be given to the examination of the financial incentives and disincentives for families of disabled persons resultng from policies for cash benefits, health insurance, housing, and

employment programs for persons with disabilities.

C. Priority for federal research support should be given to the restablishment and maintenance of a comprehensive data base on adult services for disabled persons. Such a data base system should monitor policies among state governments, administrative and service component characteristics, demographic and other functional characteristics of disabled persons.

D. Priority for federal research should be given to the study of the quality of adjustment for pre-and post-PL 94-142 families of disabled persons.

E. Conduct national experimental studies to identify parent perceptions of needs of services for disabled persons.

F. Conduct longitudinal research on the impact of parent education efforts.

G. Encourage states to develop research on development efforts to obtain data base on actual unmet needs.

H. Develop model demonstration programs to address the unique parent education needs of parents from inner-city areas, rural settings and cultural minorities.

5. Recommendations/Implications for legislation.

A. Each state should have a designated single point of referral to adult services for individuals who would be considered to have a poor prognosis for living and working independently at the time they leave school.

1 Referrals should be initiated by the schools in consultation with the family, at least three years before the students anticipated exiting date.

2. Individualized Transition Plans should be developed at least two years prior to the students anticipated exit date.

3. Case management must be required and a tracking system developed to monitor progress during transition. The tracking system should be managed by the agency or office responsible for the single point of referral.

B. States should establish programs which provide preference to contractors with disabilities to enhance the development of supported work program such as work crews, enclaves, and other competitive employment opportunities for disabled citizens. These programs could be similar to the Javits-Wagner-O'Day programm (a priority for blind or severely handicapped in Federal contracts).

C. Congress should mandate the critical evaluation of alternative definitions of "disability", short- and long-term effects of said alternative definitions upon public policy in income and health care support programs for the disabled. Subsequent to the report to Congress on said research, a common definition of both partial and total disability should be established for use in all federal disability-related programs.

Switzer Scholar Kiernan

Chapter Six

Employment: A Vital Process in Transitions

By William E. Kiernan

Introduction

Webster defines transition as the passage from one state, stage, place or subject to another. It is a change. However, it does not tell us how it occurs, why it occurs, what impact transition may have, or who or what is changing. All we can glean from the dictionary is that there is a movement.

During the past decade there has been an increased focus on changing the service delivery system such that a wider range of individuals could be served by that system. Research results are showing that the currently designed vocational and employment service delivery system does not facilitate change and that can often discourage change. Thus, if the system does not encourage change, it is highly unlikely that the individuals who are served by the system will in fact change.

An effective transition requires a change in not only the individual but the system which impacts upon that individual. The following section will look at the signs of social change as we move away from responding to people in groups and look more closely at their individual needs. Thus transition will be viewed from both a systemic and an individual perspective.

Systemic Transitions

In examining employment from a policy or social change perspective, it is beneficial to review other major social change initiatives to see what can be learned. The movement towards integration of all minority groups is not new but has been a national thrust since the days of the civil rights movement. Such social policy change initiatives reflect a major shift in societal perceptions, attitudes, and finally behaviors. It is not a shift which occurs rapidly nor is it one which occurs without major effort and often great sacrifice on the part of many.

A special minority group which in the early periods of the civil rights movement was not part of that effort, was the individual with a disability. A specific focus upon the movement of individuals with disabilities into the mainstream is reflected through legislative and administrative initiatives over the past two decades. Deinstitutionalization, the Education of All Handicapped Children Act (P.L. 94-142), and now the employment initiative for adults with disabilities have all served to call attention to this minority group. These changes reflect both consumer and civil rights issues and, as in any social policy change effort, will require major modifications in the methods society and its individual members will utilize in responding to the concerns and needs of this minority group.

One result from this social change movement has been a focus upon the disabled individual and his/her rights. In response to the deinstitutionalization process and the recognition that large institutional communities tend to ignore the needs of the individuals residing in these institutions, there was a mandate to establish individual service plans for each person within the institutional environment. The vocational rehabilitation system, with a passage of The Comprehensive Services Act (P.L. 95-602), also places its focus upon the development of an individual written rehabilitation plan. Such plans must develop a comprehensive employment related service goal based upon a full evaluation of the abilities and needs of the individual. This plan must reflect the needs of the individual and provide the individual with an active involvement in the development of the plan.

A central element of the special education service, as part of P.L. 94-142, has been the individual education plan. Again the role of the parent, the student, and the educator is to focus upon the needs of the student and develop a specific set of goals and objectives which will assist the student in progressing in the educational environment. No longer does the school dictate the educational course to be followed but a partnership of all concerned must work as a team to develop the goals and objectives of the IEP.

Movement toward the transition from school to work has stimulated calls for the development of individual transition plans. Such plans would look to facilitating the movement of the students from school to work. In many states due to the intensive focus upon achieving the mandated goals of the Education of All Handicapped Children Act and its state corollaries less attention has been paid to the issue of what happens after school. Some states, such as Massachusetts, have passed legislation such that all students who are to graduate within a two year period must have an individual transition plan. This ITP must indicate not only the services that will be needed but also stipulate the agency which should provide or coordinate such services. Such legislative mandates reflect the need to facilitate a smooth transition from school to work.

Given the focus on employment it is not surprising to find some professionals and family members advocating for the development of individual work plans for persons with disabilities. The intent of such a plan would be to assure that there is a specific effort to secure real work for disabled persons. The current service delivery system has many impediments to achieving this goal, particularly for adults who are severely disabled.

When looking at all of these changes two common elements emerge: The focus on the **individual** and the development of a specific **plan** to respond to the needs of that individual.

Lessons To Be Learned

Taken in its entirety as a social policy movement, what has been learned through deinstitutionalization and The Education of All Handicapped Childrens Act can be useful in forecasting what can be expected as the move toward expanding employment opportunities for adults with disabilities progresses.

In examining the process of deinstitutionalization, a number of observations can be made:

- movement into the community is not as easy as anticipated for the mentally retarded individual, the family, the neighbors, and local government;
- there is a need for many different designs if all are to be accomodated within the community;
- there is a need for more than a place to live if we are to be responsive to the whole person;
- there is a need to develop strategies to respond to those very special and often intricate life circumstances;
- as the needs become more complex the responses must become more individualized and thus more costly;
- group placement is not wrong if it is for the benefit of each of the individuals in the group rather than in response to some externally perceived need or mandate;
- beyond some critical number, the less likely it is that there will be a formulation of a true group culture; and
- the natural environment provides numerous constructive opportunities for training.

The Education of All Handicapped Children Act supports the principle that most, if not all, special needs students can be educated in the natural academic environment. A number of observations can be drawn from this movement as well:

- learning does occur for all individuals when appropriate settings and teaching strategies are utilized;
- students, both special and regular needs, learn from each other;
- mainstreaming is not an end but only a means to an end-- increased integration and learning are the ends;
- education is not a process conducted in isolation of the needs of the total person;
- students can and must be involved and play a critical role in all decision making activities; and
- education, particularly special education, must have a career focus.

Likewise, from the employment perspective, a number of observations can be made. These observations, however, must be based upon much less experience than those noted about. Such observations include:

- many adults with disabilities can be employed with and without supports over time;

- movement to employment does not always reflect sequential steps especially for the more disabled individual;
- there is a need for education to be more involved with the transition to employment for special needs students;
- industry is ready, willing and able to provide employment for adults with disabilities;
- industry is not a human service agency-- its mission is to make a profit;
- the natural work setting is a highly effective tool in training the adult with disabilities.

Though not an exhaustive set of observations relative to the issues of deinstitutionalization, mainstreaming, education, and employment it is clear that there are consistent themes throughout. The employment initiative is a continuation of this social change effort to expand upon the utilization of the natural setting for persons with disabilities. This initiative focuses upon a real work setting as a means of increasing the level of economic self-sufficiency realized by the adult with disabilities.

Individual Transitions

The systemic transitions noted about reflect changes in societal views, perceptions, and beliefs. Though in fact much greater than movement to employment, the second set of transitions, for purposes of this paper, considers the individual and the changes which must occur as movement toward greater levels of economic independence are achieved. This second transition must also reflect changes in a series of views, perceptions, and beliefs.

All too often the focus upon employment or what to do after school, begins after graduation. This is in fact the time when the implementation of a transition plan should be taking place however, the development of the plan should occur prior to this time.

Employment is a complex process, one which has many sides. As in any such process, there are a number of tenants or truisims which are associated with this process. These truisims effect our belief about what employment is or ought to be. Employment is:
- an identity
- a dynamic process
- a developmental sequence

The following looks at each of these truisims in more depth so that we can understand the role employment can and must play for the adult with disabilities.

A. Employment as in Identity

One of the central themes in our culture is the perceived and real contribution an individual makes to society through employment. Often our identity is closely linked to our occupation. Beyond identity, one's occupation plays a key role in determining social activities, associates, and in many ways shapes future opinions and attitudes. Social status is frequently tied to one's occupation.

B. Employment as a Dynamic Process

Employment should not be viewed as a term which is synonomous with job but rather employment is a reflection of the several jobs an individual may occupy during their working years. An employment history is thus a representation of multiple jobs. Each job reflects the level of skill, maturity, and motivation that is possessed by the individual worker at a specific point in time. Few of us are in our first jobs but rather have progressed through several jobs. Employment should, thus, be viewed as a dynamic state, one which reflects an individual's evolving level of ability, social maturity and training.

C. Employment as a Developmental Sequence

Just as employment is a dynamic process, the development of vocational interest is likewise an evolving process. It does not come at the time of graduation from high school, college, or graduate school but rather is a reflection of many different stages in one's life. Employment can thus be viewed as developmental.

Klayman (in press) notes that prior to the age of 11, most individuals have a rich fantasy life and that this in fact plays a key role in the vocational interest and career development process. It is not uncommon to have a young child go through a series of stages reflecting the desire to be:
- like Mom and Dad;
- like Uncle George, Aunt Mary or a specific neighbor;
- like the policeman or fireman, doctor or nurse, or member of some other highly visible helping occupation.

These steps are not surprising in that they are reflective of the substantial bonding which develops between the parent and child, the tendency as the child grows to expand the circle of influential people, and the desire to be viewed as helping others and thus considered "good" by others.

From the fantasy stages, reality and the influencing factors not in or related to the home, play a significant role in the refinement of vocation interest. Several stages emerge as reality enters the vocational interest process. These stages reflect:
- peer pressure and wanting to be liked by age mates;

- a growing knowledge of what in fact is involved in various occupations;
- an opportunity to develop and test out real skills in specific interest areas;
- a chance to try out different jobs developing first hand knowledge and experience which will ultimately contribute to the establishment of an employment history.

The influence of others and a growing awareness of true vocational interest in relationship to capacity, assists the individual in moving from the wish stages to understanding and focusing on real opportunities.

These truisims to employment clearly show that the evolution of the vocational interest and the attainment of employment is a result of the process which occurs over several years. Parents, educators, rehabilitation professionals, and the individual with disabilities must all work together if a truly comprehensive plan which is responsive to individual needs is to be developed.

In addition to the truisims of employment, there is also a recognition that employment is only part of the rehabilitation process. Employment does play a key role in developing identity, economic independence, and social contacts. However, it does not represent the majority of the time available during a week. In fact, employment represents about 25% of the available hours per week if the individual is working 40 hours per week. Attention must also be given to the residential and learning and adjustment needs of the individual. To deal with one set of needs with no or little attention paid to the other major areas of life activity will only serve to fragment any total rehabilitation effort and reduce the chances for achieving a positive outcome. It is mandatory that the needs of the whole person be considered as a comprehensive plan is developed.

Vocational Choice Model

From the economic and psychological perspective, the world of work for both the individual and society is significant. As was noted above, formal preparation in school must be directed at viable outcomes for the student as an adult. Society, on the other hand, must provide a means through which the individual can enter as a worker. In analyzing how individuals move from school to employment a series of steps must occur. These steps are not always predictable but do appear to reflect some order or sequence. The thrust of any model which reflects these employment pathways must be focused upon the individual and not the system or the available slots within a service delivery system.

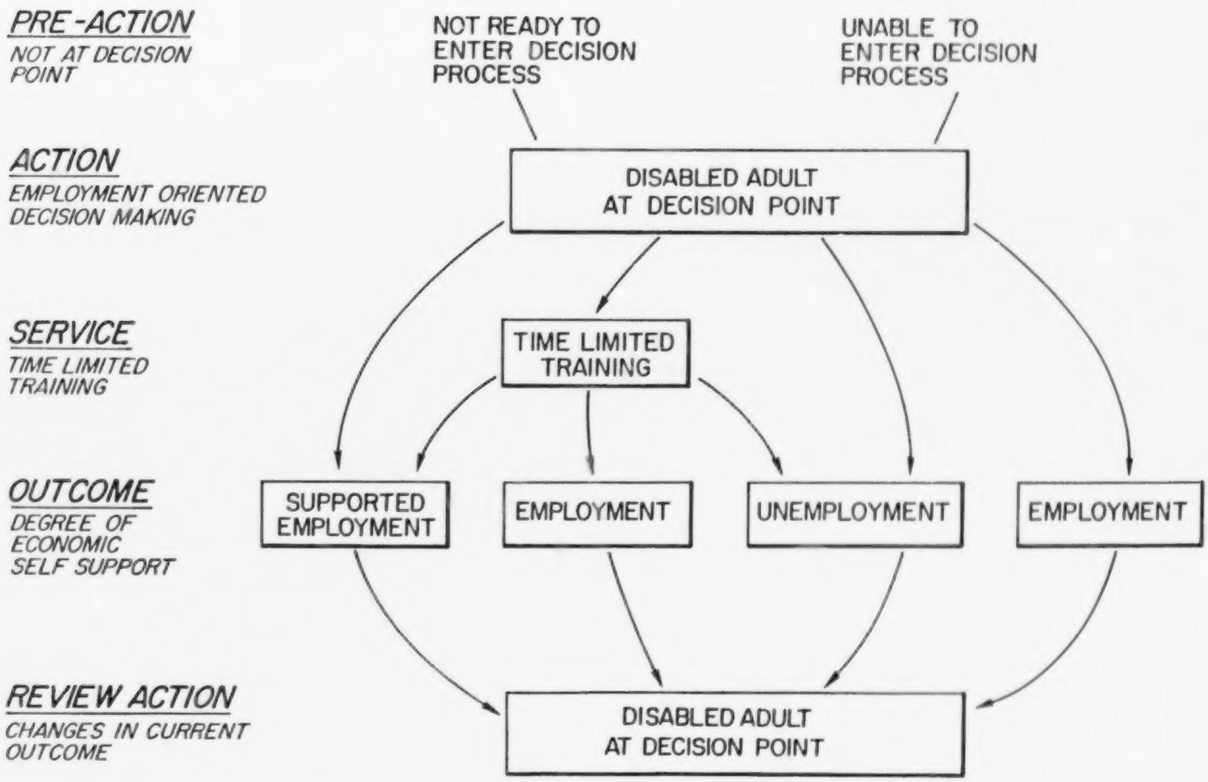
The Pathways to Employment Model (see Table 1) presents a conceptual framework which looks at the role that adults with disabilities play in the employment decision making process and the outcomes which may be achieved as a result of that process. This model reflects substantial deviations from the flow-through design of the traditional vocational rehabilitation model, in that it places less emphasis upon sequential training or service activities and more upon simultaneous options, choices, or paths for the individual. Some of the more traditional views of vocational training activities, however, are also incorporated into this model.

The pathways model presents a framework within which the individual may make choices. It is a person-driven design where the individual is faced with a number of choices all of which lead to an outcome of enhancing the degree of economic self-sufficiency realized through employment. Such an outcome looks not at individual job placements, but rather at the effects of moving the individual into an employment status. Employment status should be viewed as a series of jobs acknowledging job turn-over not always as failure, but in many cases as a sign of occupational growth and development. The measure of effectiveness or success in such a design is thus not job placement or "26" as in the vocational rehabilitation system, but a measure of earnings in relationship to level of financial independence realized by the individual.

A key concept of the design is the focus upon expansion of environments in which outcomes should and may occur. It is more than the creation of specific jobs, it is an attempt to look at work environments and see what potential exists for the worker with disabilities in the widest variety of industrial and community settings. The design encourages exploration and establishment of new environments and new methods in which the adult with disabilities may attain and maintain or be maintained in an employment status; thus, an asset to society rather than an economic liability.

1. Elements of The Pathway Model

The Pathway Model, while focusing on the range of choices which should be available to the individual as the move toward employment progresses, points out the need to expand the environments within which employment can occur. Though the model does not stipulate the type of employment sought, past research has shown that the industrial or real work setting is one which is most conducive to increasing the productivity and thus expanding the degree of economic self-sufficiency realized by the individual with


PRE-ACTION
NOT AT DECISION POINT
ACTION
EMPLOYMENT ORIENTED DECISION MAKING
SERVICE
TIME LIMITED TRAINING
OUTCOME
DEGREE OF ECONOMIC SELF SUPPORT
REVIEW ACTION
CHANGES IN CURRENT OUTCOME
NOT READY TO ENTER DECISION PROCESS
UNABLE TO ENTER DECISION PROCESS
DISABLED ADULT AT DECISION POINT
TIME LIMITED TRAINING
SUPPORTED EMPLOYMENT
EMPLOYMENT
UNEMPLOYMENT
EMPLOYMENT
DISABLED ADULT AT DECISION POINT

PATHWAYS TO EMPLOYMENT FOR THE DISABLED ADULT
A HABILITATION MODEL

disabilities (Bellamy, Horner, and

Stages in the Model

The Pathways model presents a concept of stages in the decision-making process. These stages reflect the point where an individual might find him/herself in the process of making an employment-related decision and include: an action stage, a service stage, an outcome stage, and a review stage.

The action stage reflects the point at which an individual is about to make a decision. It is at this stage that attention must be paid to providing the individual with information about available options and the specific parameters of each option. It is imperative that these options be presented in a clear and detailed fashion so that they may be understood by the adult with disabilities. The action stage leads to either a service stage or directly to the outcome stage.

When the decision made by an individual is to obtain additional skill development prior to moving into an outcome, specific services may be accessed. In this stage the individual typically has a general awareness of what he/she would like to do and an understanding that additional skills to attain this goal will be necessary. The nature of the training or services offered should assist in the development of the skills which will lead to the ultimate outcome sought. Thus, to enter a training program focusing on knowledge of tools when in fact the individual is interested in working in a service area is inappropriate. Equally inappropriate would be entry into a program of work adjustment where the role models in the training environment continually demonstrate unacceptable work behaviors. Thus a training environment available in a sheltered work setting may have limited value in assisting this individual in developing appropriate work skills and moving towards his or her desired outcome. Once the service or training is completed, movement into the outcome stage occurs.

Rather than present employment as the outcome, the Pathways Model defines outcome as the degree of economic self-sufficiency realized through employment. The outcome can be positive as in the case of employment or supported employment or negative as in the case of unemployment. Whatever the outcome achieved, it must be a reflection of the individual's informed consent and not what others think or feel it should be or what happens to be available at the time. The pathways to the desired outcome, as presented in the model, are varied and diverse reflecting the range of abilities, interests, and degree of motivation brought by the individual into the employment-related decision making process. As will be discussed later on in this chapter, each activity leading to the outcome has different characteristics and qualities.

As in any dynamic model there must be a mechanism to assure that an individual can modify his or her current status, in this case employment, supported employment or unemployment, so that a more desirable outcome can be achieved. In the review action stage, there is an opportunity for the individual to re-examine his/her decision and when necessary modify that decision. Change need not be viewed as failure, but rather, in many cases, as a maturing process. As a result of this stage, the individual is brought back to the employment-related decision or action stage. At this point, the entire process is repeated where the individual again has access to services leading to outcomes or goes directly to an outcome.

The stages of the Pathway Model are intended to represent those stages through which all individuals go as they progress towards increased levels of economic self-sufficiency. For some, the level of complexity in the decision stage may be greater than others, however, the process and stages will be the same. Thus, the Pathways Model should reflect the normal growth and development model used by all as vocational decisions are made.

Components within the model

Having looked at the stages of the pathway model, a closer look at the components may serve to elucidate some of the underlying concepts of the model. Individual choice and simultaneous options at the employment related decision point serve to make the model a person-driven design.

The more traditional vocational rehabilitation design is incorporated into the pathways model. The service stage reflects the movement of the individual through a time-limited training program which will lead to either employment or supported employment or to unemployment for those not completing the process. Time-limited training may take many forms ranging from specific skill training, to work or personal adjustment training, to on-the-job training. The emphasis of time-limited training services is upon specific and discrete supports which would be discontinued as the individual moves toward the goal of increased economic self-sufficiency. The trend in many training approaches is to provide the service in the natural work setting as often as possible.

Upon completion of the time limited training stage, the adult with disabilities moves toward one of three outcome options; employment, supported employment or unemployment.

Employment is viewed as the entry of the individual into a normal work setting. The level of expectation and degree of support provided is no different than that provided to all employees once the task has been learned. The pay received should be at least minimum wage or at the prevailing wage rate for that specific job. Though there may be a need for some accomodation initially, ultimately the expectations and wage rates for the worker who is disabled should be no different than for the worker who is not.

Supported employment is an employment option which recognizes the capacity of the adult with disabilities while acknowledging his/her need for ongoing support. The nature of the supports required will vary depending upon the individual and the environment within which the individual works, resides, and socializes. The supported employment option looks more at the supports which will enhance degrees of economic self-sufficiency thereby making the individual with disabilities less dependent upon others for economic support. For many entering supported employment, the level of reimbursement will be less than those in employment since it is expected that the productivity for individuals in supported employment will be less than that of the average worker in industry.

A word needs to be said about those who choose not to go into employment, the unemployed. As in the case of the non-disabled population, there are those who for numerous reasons choose not to work. From an economic perspective, full employment does not imply that everyone will be employed but rather that there will be a residual group who will choose not to work, be in transition between jobs, or unemployed due to economic issues (Poindexter, 1981). Full employment is viewed by many economists as the event where there is a job available for everyone who wants to work at the prevailing real wage. In terms of measured unemployment, most economists would accept an unemployment rate in the 4.5 to 5.5 percent range as full employment. Such a definition acknowledges that about 5% of the total labor force population may choose not to enter employment. This level of unemployment should also be applied to the population of adults with disabilities.

The various components of the Pathways Model lead to the common outcome of impacting upon the degree of economic self-sufficiency realized by the adult with disabilities. The establishment of a singular outcome allows for evaluation of the various paths an individual takes when making an employment related decision. Less emphasis is put upon the concept of case closure or placement since there is a recognition of job mobility within the model. For some, continuous intervention will be necessary, others will require intermittent support, while still others will progress to full independence.

Employment Strategies and Designs

In light of the pathways design a number of services and support options must be available if the full range of choices for the adult with disabilities is to be a reality. Two major categories of service options exist, those that are time limited and those that are ongoing.

A. Time Limited Strategies

As we noted earlier, time limited options reflect the more commonly provided vocational rehabilitation services including work adjustment, on-the-job training, and others. A number of specific designs exist which reflect the time limited concept of training including but not limited to Transitional Employment Programs (TEP), On The Job Training (OJT), Job Training Partnership Act (JTPA), National Industries for Severely Handicapped (NISH), and Projects With Industries (PWI) to name just a few.

The common thread is that of intensive supervision with the expectation that employment without supports will be realized in the future. This concept is not new and in fact has been around for many years. Each of these designs has some variation in the nature of the service offered or the target population to be served. Most frequently, this is a reflection of the legislative or administrative mandates which have established the employment and training program.

The Job Training Partnership Act (JTPA), latest of the federal efforts in large scale training initiatives, has had many predecessors. The thrust of the program is aimed at those having major problems entering the labor market.

Over the 100 year history of employment and training programs nationally, the trend has been to increasingly delegate detailed planning and program operations to the state and local levels through local school districts and an emerging nationwide system of employment and training agencies.

One of the most notable of the employment and training efforts was the Comprehensive Employment and Training Act (CETA). This act united training programs for the disadvantaged with public service employment in a federally funded system operated by local government. The CETA projects were designated to aid public or private employers at the local level. The focus of the CETA effort was directed at insuring an adequate supply of workers with the needed skills, attributes, and behaviors. To this end, a number of educational and training services and special skilled training programs were designed to prepare chronically unemployed and disabled persons to meet the special employer needs.

The subsequent legislative initiative, and The Job Training Partnership Act (JTPA), was designed to restructure the local planning framework such that there was an increased involvement of business and an expanded training focus. JTPA eliminated public service employment and greatly reduced work experience programs. This act shifted employment and training efforts to be more responsive to the supply side of the economy. Authorized activities and broad detailed requirements are few and authority is provided to plan for the bottom up with maximal input from industry through mechanisms such as private industry counsels (PIC). The JTPA program reflects employer-based needs rather than client centered training (Knuti, 1984).

In both CETA and JTPA, the focus was and is on the provision of services to low income unemployed persons. For JTPA this reflects a mandate of 90% of those served being low income and 40% of those considered as youth. Displaced workers, handicapped, and a limited number of others having severe obstacles to employment but not disadvantaged could be served (a total of 10% of the participants). As a result of such mandates, these systems were not a major factor in the employment of adults with disabilities. The persons with disabilities who were served were seldom severely disabled and often were capable of participating in the training activities offered. More severely disabled persons tended not to be viewed as eligible clients unless a specific state or PIC had a special interest in this area.

Another major federal initiative which is having an impact upon the employment of persons with disabilities is the Javits-Wagner O'Day (JWOD) Act, P.L. 92-28. The main purpose of this act is to provide meaningful employment opportunities for people with severe disabilities and to promote their placement into competitive industry. In 1974 the National Industries for the Severely Handicapped (NISH) was established to provide technical assistance to sheltered workshops. Among other activities, NISH conducts research and development to identify commodities and services which are feasible for sheltered work centers. Thus, this act allowed certain sheltered workshops, by bidding on commodities for the government, to establish a level of consistency in contracting not possible before. The addition of service contracts has allowed facilities to move out of the confines of the sheltered workshop into the community to perform contractual service activities. Though the project was slow in starting, as of July 19, 1985 it boasts of more than 12,000 placements with 212 work centers maintaining commodity or service contracts.

A major advantage of this federal project is that once a contract is awarded it is retained by the work center for as long as the government buys the commodity or service. A potential limitation is that, particularly in the commodities areas, there can be an incentive for work centers to retain good workers and in fact reduce placement into independent industry-based settings. The project has had some impact particularly in the service areas on the movement of persons with disabilities out of sheltered workshops and rehabilitation programs.

The above noted federal initiatives have provided an opportunity for some facilities to begin to transition their rehabilitation programs from a sheltered employment focus to a transitional employment focus. The TEP design is a time limited design where facilities will utilize the natural work setting to train individuals in skill acquisition as well as adjust to the work setting. Strategies such as on-the-job training (OJT), work crews, enclaves, and supported work programs have been developed in many states. Though there is seldom concurrence in terminology, there is concensus on some of the principles which these TEP options adhere to. The basic principle is one which acknowledges that the natural work setting is an effective and efficient environment to train persons with disabilities. The interaction with persons who are nondisabled and the opportunity to model others' behaviors is greater in such settings. The opportunity to both train the individual worker and support the supervisor in the initial period of employment for the worker with disabilities serves to reduce apprehension for the individual with disabilities as well as cost for the industry. For the worker with disabilities this mechanism provides an opportunity to learn the task over a longer period of time and become more familiar with the work setting.

A TEP model can provide fiscal supports to the industry as in the case of on-the-job training or targeted job tax credits (TJTC). This economic incentive in certain cases can be the lever which will open the employment door for the disabled worker.

Two variations of the TEP design exist. In one, the roll-over design, the supervision is faded as in the case of the OJT and many supported work option. In the other, the placement design, the individual is trained and then placed out into a similar job. In the latter case specific supports will be necessary during this transition period. Such supports may include the use of an Employment Training Specialist or job coach who will support the individual on the job and then fade out the supports as the production rates increase and the adjustment to the job progresses.

The roll-over model, where the supervisor is faded out and the client is left in the work setting, does not deal with this transition point but rather focuses the effort on adjustment to a specific company and specific job. This model may have reduced costs initially, however, it requires that a new group placement will need to be developed each time if an agency is to continue the use of this design. Both designs have the common focus of training in the real work setting and fading supports over time such that the individual will be in unsubsidized employment at some point in the future.

B. On-going Support Strategies

The second option, ongoing supports in the real work setting, is a more recent strategy in the delivery of employment services to persons with severe disabilities. Supported employment, a type of employment service, is a combination of employment and ongoing support. It should be viewed not as a program prototype or activity or even a method of employment preparation but a type of employment. It is a method of insuring normal employment benefits, providing ongoing and appropriate support, creating opportunities, and achieving full participation, integration and flexibility (Bellamy and Wehman, 1985).

Supported employment is defined as paid employment for persons with disabilities for whom competitive employment at or above the minimum wage is unlikely and who because of their disabilities need ongoing support to perform their work. The nature of support offered is variable and may include training, supervision, and transportation. Several features of supported employment set it off from the time limited options.

The key focus of supported employment is to place the individual in employment where wages, working conditions, and security are viewed as essential components. The support offered is directed toward getting and maintaining a job rather than preparing for the job. Social integration is a significant element of the supported employment option where the emphasis is on relating to nondisabled co-workers at work and out of the work place. By the very nature of the design of supported employment, more severely disabled persons are appropriate for participation.

Several different designs of supported employment have emerged. These designs include but are not limited to enclaves, work crews, and supported job placements. Each design conforms to the basic tenants of supported employment while being able to respond to individual needs and the economic environment in which the work is produced.

The enclave design is one in which a group of 6 to 8 individuals will work as a single unit in an industry. Typically the enclave is located in a production or manufacturing area with the supervision being provided by the sponsoring agency or rehabilitation program. This design is one which can accomodate those individuals who may demonstrate inappropriate behaviors as well as those who may require longer training periods to meet productions levels. Enclaves are often administered by an outside agency on a contractual basis. This need not always be the case, however, more frequently then not, industry will be reluctant to assume full responsibility for this type of supported employment option.

The work crew design is similar to enclave, however, it tends to deal with service rather than production jobs. By the very nature of the tasks performed, the social and production capacities of the participant workers is higher than those in an enclave. The crew program frequently allows for greater integration and provides for a wider variety of tasks to be performed. The administrative structure of the crew concept is similar to the enclave in that a rehabilitation agency or facility often assumes the majority of the responsibility for the day to day operations of the project. The crew program has some capacity to respond to the employment needs of persons with severe disabilities living in rural areas as well.

The supported placement design is one that looks at the individual placement of persons with severe disabilities providing direct assistance through the use of an Employment Training Specialist or a job coach. The nature and amount of the supervision provided will vary depending upon the needs of both the individual and industry. Initially the support offered will be intensive with this being reduced as the individual learns the tasks and increases productivity. The focus of the support beyond this point will shift to that of assisting the individual in being assimilated into the work environment and responding to the special issues or concerns as they arrive.

As can be concluded from the above discussion, the nature of supported employment is varied and the designs utilized are reflective of individual needs and demands of the marketplace. The essential element of the supported employment design is one of placement rather than training toward placement for individuals with severe disabilities. Such a design cannot be successful if in fact support on site is not available.

The activities of national programs such as NISH and PWI can serve to expand employment opportunities when facilities focus upon the use of the natural work setting. A good example of this has been the efforts to use the service contracts of NISH to move severely disabled persons out of sheltered employment and into real work environments with ongoing supports.

Considerations for the Future

In the case of both employment and supported employment, the jobs done can be diverse, however, the environment within which the job is performed should reflect the natural or real work setting. From a planning and development perspective there is a need to look at expansion of the types of jobs available as well as the environments in which employment options can occur. In certain instances, the environment can be an integrated one, while in others the amount of stimulation in such an environment may be too much for the worker with disabilities to adjust to. Supervision and support can be the responsibility of the agency or organization involved, or the industry, or a combination of both. With a reasonable degree of flexibility and creativity, the number and type of environments within which the adult with disabilities can participate as a worker may be expanded.

The expansion of the focus upon employment for all persons with disabilities will mandate that there be a redefinition of the industry/rehabilitation partnership. To train individuals for what is believed to be a need in industry without first documenting the need may lead rehabilitation programs to prepare individuals who will be ill equipped for entering the world of work. The concept of selling must be replaced by one of marketing where the assumption is not that "we know what is needed" but that we will find out what is needed in the employment field and train toward that actual need. A true partnership where rehabilitation is a resource to industry will serve the purpose of matching the individual and the employment environment so that productivity is enhanced.

Provision of support in industry will require a different approach to training of staff in the human service field. Awareness of industry concepts, principles of organizational behavior, and understanding the industry environments are no longer optional skills if the human service system is to have its staff be responsive to the industry environment. Support must look to facilitate the bottom line as well as the individual. Support must be integrated into the industry utilizing, wherever possible, industry resources such as employee assistance programs when available and personnel departments.

As in any business venture there must be an awareness of the economic environment in which a placement or supported employment program is to be initiated. Targeting upon jobs which have a high turnover rate will reduce industry expenses yet caution must be taken such that those jobs which are targeted are not also the same ones that would be the first to go if industry is to experience an economic turndown. Knowledge of industry trends will facilitate the identification of those jobs which are "recession resistent" and indicate where development efforts may be more stable.

Strategies to better match the needs of industry to the skills of the individual will serve to reduce job failure rates initially. However, there must also be a mechanism in which there can be an opportunity for advancement for the employee with disabilities in the future. Support systems need to be developed to respond to both the individual who is looking for a change or an advancement and the individual who is having difficulties in performing on the job. In this latter case often the root of the problem will not be in the work setting but rather external to the job. Mechanisms to provide support at the time of change and at periods when problems have emerged will be necessary. Such support will require the use of industry resources (i.e. employee assistance programs), as well as community resources to assure continued adjustment in the work environment. As was noted earlier, work, though a critical factor, must be dealt with in the context of a whole person if long term stability is to be realized.

The expanded focus on employment at the national, state, and local level is exciting. The use of the strategies of employment or supported employment as options leading to increased levels of economic self-sufficiency will serve to open up real work activities for persons with severe disabilities. This employment movement is one which looks at accessing ability and acknowledging that the role of the individual with severe disabilities is one which is positive, productive, and can contribute in an economic as well as social fashion to society as a whole.

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EXCERPTS OF REVIEWS AND COMMENTS

The following are excerpts of reviews, comments, and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as it relates to the content of Chapter Six by William E. Kiernan.

Kiernan defines supported employment as paid employment for persons with disabilities for whom competitive employment at or above the minimum wage is unlikely and who because of their disabilities need ongoing support to perform their work. I believe that the reference to ability to learn the minimum wage should be dropped. To begin with I am unclear as to whether it is referring to the ability to earn the minimum wage before supported work services are provided, or after. If after, then definition is wrong **since many severely disabled poeple can earn above the minimum wage** if given ongoing support. The critical element of the definition is that they need ongoing support. The inclusion of a low earnings capacity is defeatest in tone as well as being inconsistent with the facts.

Kiernan appears to define persons who "choose" not to go to work as unemployed. This is inconsistent with the Department of Labor definition of unemployment which defines a person as unemployed only if he or she is actively looking for work. Kiernan notes that full employment does not require that all people be employed. The residual rate of unemployment at full employment, however, should include only persons seeking work, not those who are not seeking work. Many severely disabled people would not be counted as unemployed becuase they are not seeking work. We recognize, however, that many would seek and accept work if they believed that they were able to work and if appropriate support were provided. The fact that some unemployment at "full employment" is inevitiable must be qualified by noting that this is true because inevitably some workers are in the process of changing jobs. However, it is important to emphasize that these temporarily unemployed workers do not expect to remain unemployed, and at full employment will usually locate work within a few weeks and will be replaced by other temporarily unemployed workers.

-- RONALD W. CONLEY

I must take exception with some misconceptions which appear in an otherwise excellent paper.

The employment initiative for adults with disabilities is not a recent phenomena. Indeed, it has been the focus of the state-federal rehabilitation system since 1920. What is different, is the emphasis on transitioning to maximize the likelihood that the adolescent with a disability will become the adult with a job. Another new emphasis is the supported work model and its variants for severely disabled adults who would traditionally be considered ineligible for vocational rehabilitation services because the feasibility of gainful employment is remote. Now rehabilitation, whose developmentally disabled catchment population was the middle range of special education graduates (those who were higher functioning had no need for services; the lower functioning ones were not eligible for it), is being asked to stretch those lower population boundaries and sweep in a wider eligible population.

The development of an individualized transition plan sounds like a step forward, but how does an individual work plan differ from the IWRP (Individualized Written Rehabilitation Plan)? A vocational goal, intermediate objectives and services to meet the goal are the IWRP's major components.

Kiernan notes that employment provides an identity. Tooman also comments on this in his opening statements when he captures the excitement and sense of opride that accompanies that first job. It is this excitement that professionals and parents should communicate to the student with a disability -- this is an altogether appropriate foil for the work disincentives so attractive today.

-- MARITA M. DANEK

Kiernan appears to have captured all the varied methods of transition to the workplace for disabled individuals and groups. This paper would clearly define most options to participants in the system from both the employment-employee side and the employer side. He just touches the surface of one problem which crops up in most state rehabilitation programs with which I am familiar. That is, that little transition is sought until the disabled student finishes high school -- often, too late to plan a transition program. We need to find ways of attracting our students with disabilities in high school to the vocational rehabilitation resources.

I very much appreciated Kiernan's remark that industry is **not a human service agency** -- its mission is to make a profit. However, since our human resources are our most valuable asset and even the "normal" high school student comes ill equipped for work readiness in far too many cases, we have to be prepared to train and retrain all of our personnel.

Employers have a difficult cost problem to address in today's employment market. That of employee medical care coast. One of the areas of incentive desperately needed today in some joining medical care cost coverage for the more severely disabled -- particularily those that the potential employer can expect future high medical care costs. Though, we as an employer in PWI (Projects With Industry) have not experienced this, it is the one question I get most often from other local area employers. A government assistance for catastrophic disabled persons medical care as well as tax incentives for aiding in the purchase of perishable prosthetic devices would encourage many more employers to employ persons with disabilities.

--ELIZABETH DEMPSEY

The significant underlying premise of Kiernan's treatment of this paper is the concept that employment be viewed as a process providing the individual with degrees of economic self-sufficiently in contrast with the traditional/vocational rehabilitation view of employment as job placement, or case closed.

Kiernan traces the systemic transitions related to employment taking place over the past 25 years, i.e., (1) Civil rights and affirmative action, (2) deinstitutionalization, (3) Education of All Handicapped Children Act, (4) employment initiative.

Implications drawn from this treatise are that in the transition to reach process:

A. The Pathways to Employment Model is a conceptual framework in which the individual makes choices (person-driven design) with emphasis upon option, choices, or paths.

B. Success in employment attainment is a result of a team effort of several year duration, including parent, educator, rehabilitation professional and the individual with a disability working together to develop a comprehensive plan.

C. Employment should be pursued in context with the attention to the other needs of the individual.

D. The "real work" setting is most conducive to increasing productivity and thus the degree of economic self-sufficiency.

E. Sheltered workshops and rehabilitation centers present an environent where role models continually demonstrate unacceptable work behaviors.

F. Industry is ready, willing, and able to provide employment for individuals with disabilities.

G. Options available to individuals with disabilities are: (1) competitive employment, (2) supported employment, (3) unemployment.

H. Both time limited strategies and on going support strategies should be carried out in the real work environment.

The large question that is raised and which needs both market research and a strategy is the relative acceptance, commitment, and involvement of the business community on the entire process. Perhaps a strategy that seeks business expertise and counsel at the earliest stage of the transition process needs to be addressed.

Kiernan hints at this need in his future considerations, i.e., a mandate to redefine industry/rehabilitation partnership.

Although market place reality for the nondisabled worker as well as the worker with a disability often involves high turnover jobs which are vulnerable to economic turn down, Kiernan again hinted at a strategy that needs to be addressed, i.e., the market place as a market, segmenting the market, and targeting the market to acquire the best results.

This paper presents a strong argument for the individual-centered approach to transition to employment and economic self-sufficiency and a **Pathways to Employment Model** that appears workable.

A concurrent strategy needed that will ensure all this is in fact workable is a market-driven strategy that will focus on the needs, wants and problems of the business and industrial community and how bringing to the market place individuals with disabilities, whether for competitive or supported employment is going to result in an improvement of businesses bottom line or at the very least no negative impact.

The paper provides a direction for exciting challenges and opportunity.

-- CARL V. PULEO

Overall, the paper presents some very good and appropriate content. However, lack of specificity and/or documentation in support of some assumptions and conclusions detracts from the impact of the paper. For example, the author states that "Research results are showing that the currently designed vocational and employment service delivery system **does not** facilitate change and that can often discourage change." What research?

What vocational and employment service delivery system? Is change equated with the Webster definition of transition provided in paragraph one? If so, the definition is so broad that it is doubtful that any research would support **no change** occuring through current systems no matter how defined. Another example is the statement regarding obtaining "real work for disabled persons," that the current service delivery system has many impediments to achieving this goal, particularly for adults who are severely disabled. Identifying the system and the impediments would have enhanced the impact of this section. Yet another example leaves the impression tha employment-type programs have a **more recent history** than those reflected by deinstitutionalization or P.L. 94-142.

The author's discussion of the "Pathways to Employment Model" is apparently too brief to convince this reader that it, as he concludes, significantly differs from the current vocational rehabilitation process. A close look at what is discussed as process and outcome of the model present many more **similarities** than **differences.** In terms of outcome, the author states that unlike the successful placement, ("26"), model of VR, his Model measures the effects of successful employment and then later talks about the common outcome of the Pathways Model impacting on the degree of economic self sufficiency. From the arguments provided, it is difficult to see how this differs from VR's remunerative employment goals.

Within the section on **Consideration For the Future,** ideas inherent in the Partnership With Industry (PWI) needs have been addressed and are on-going within RSA supported Projects With Industry as well as through long term and short term training efforts within the State-Federal Cooperative Vocational Rehabilitation program. The need to expand these efforts into transitional efforts is obvious.

These constructive criticisms hopefully can enhance the impact of the paper. The singular importance of the employment and transition movement within this country in providing us with the potential to devleop **renewed** and **new linkages** across Vocational Rehabilitation, Special Education, and Vocational Education must be aggressively pursued to insure that all individuals with disability in our society can access appropriate employment. Much needs to be done and this paper adds significantly to the communication process required to initiate these efforts.

-- AMOS SALES

In this paper, Kiernan discusses several changes needed in the current vocational and employment service delivery system. There are three points that "hit home" with me and I would like to emphasize: (1) the importance of providing the disabled individual with many viable options and opportunities for training and employment, (2) provision of training which follows labor market trends, and (3) a realistic view of business and industry's role in placing the disabled employee.

One problem often facing the individual who is considering his or her future vocation is a lack of exposure to the "working world" and little knowledge of vocational options. In my opinion, an excellent time to begin this vocational exploration is during high school or perhaps even junior high school, Kiernan states, "there is a need for education to be more involved with the transition to employment for special needs students." Consideration of what a student will do after graduation should not be left to graduation day or even the senior year of high school -- but should be given attention throughout his/her school years. Students can be exposed to various vocations via field trips, temporary work assignments or part-time placements.

Secondly, Kiernan's point that there must be a redefinition of the industry/rehabilitation partnership is a crucial one. Rehabilitation programs which intend to be a "resource to industry," must research the needs of industry and train disabled workers to meet those needs. Far too many of today's rehabilitation programs train individuals to be assembly-line workers, machine operators, file clerks, etc. -- positions for which there is little or no demand in business and industry. If communication between industry and rehabilitation is clear and ongoing we will be able to meet each other's needs more effectively.

The third point which I would like to emphasize ties in closely with the second. Kiernan makes the observation that, "...industry is not a human service agency -- its mission is to make a profit..." Business cannot be expected to make allowances for individuals who do not meet minimal productivity levels or have the necessary skills to perform a specific job. This is not "reasonable accommodation." Employers should be encouraged to make accommodations to the work space, if necessary, so that individuals who are disabled will be able to perform the job at the required productivity level.

If more emphasis is placed upon **vocational education** and exposure during school years and a greater effort is made to understand **labor market trends** and the way in which business operates. I beleive that rehabilitation will have made a giant

stride in improving its service delivery system.
-- ALLEN R. SEARLES

Within the parameters of Law and Regulations, the vocational rehabilitation service delivery system has been able to facilitate change. To this extent I take issue with Dr. Kiernan's opening statement which includes the vocational service along with what is assumed to be the State Employment delivery system in the reference to research results which show the system cannot facilitate and often discourages change. Change has occurred in many aspects of vocational rehabilitation services. Examples would certainly involve a movement from a moderate/non-severe service population to a demonstrated capacity to serve severely disabled persons through the provision of a broad spectrum of service options. While we submit that vocational rehabilitation has not traditionally taken a "proactive" position in terms of projecting future ssrvice demands, it has over recent years been making substantial adjustments in this regard. Demonstratively, those adjustments have been seen in the expanded capability and services to learning disabled persons, chronically mentally ill individuals and the multiply handicapped, and the establishment and implementation of Independent Living Rehabilitation Programs. It has also been observed that VR has placed a greater emphasis on the training needs of practitioners in order to provide improved and effective services to new disabled populations, i.e., those groups not previously served. While economic conditions have recently precluded or restrained efforts to recruit specialized personnel, relevant continuing education and training has increased the skill levels and knowledge base of rehabilitation professionals to better serve specific disability groups. Vocational Rehabilitation recognizes fully the service delivery systems' position in an ever-changing environment, and are better prepared today to confront those changes than in years past.

In further reaction to the author's attention to "Employment: A Process in Transition," I would add 'prepared/qualified' to his statement that "industry is ready, willing and able to provide employment for adults with disabilities." The mere presence of a disability will not, nor should it, prompt an employment situation. The educational and service delivery systems have a product to market and that product must demonstrate the ability and capability to perform the needed job function. While I can agree that a "natural work setting is a highly effective tool in training the adult with disabilities," simulated work environments can occur through other options. These options should be explored in all instances where suitable job sites cannot be acquired.

Finally, an issue that must be confronted in public reactions to non-time-limited support mechanisms are those needed for transition employment programs and supported employment. Public reaction at this point in time has not been extensively tested. Most publics are unaware that demonstrations and pilot projects are being undertaken. If we are, as we say, concerned with positive outcomes we need the support of employers, community, local governments and significant others. We should now be articulating the merit, worth and cost benefits of the transition effort to a broader audience as part of the employer -- public orientation process.

Sustaining the supported employemnt concept, which is currently focused primarily on production or manufacturing areas, raises some "futuristic" concerns. Recent trend data and research finding show a movement away from manufacturing industries to a more service-oriented economy. If indeed we are to collectively move toward a service delivery system inclined to strategic planning, we need to be considering the impact of a service industry and the future demands of the market place in preparing severely disabled persons for employment. Here again, it will be important that we have a marketable product, i.e., job-ready clients to meet identified job needs.
-- MIRIAM E. WALKER

It was a pleasure to read this highly creative paper by a leader in the field, a person who has clearly shaped the roots of the current movement. There are a number of positive aspects of this paper to which I would like to call attention. Building upon the basic theme of individual transition. Kiernan discusses employment as an identity, as a dynamic process, and as a developmental sequence. He correctly notes that residential and learning and adjustment needs are also paramount. Vocational choices are viewed as being crucial to the employment process.

The major contributions of this paper is the **Pathways to Employment model.** This model focuses on job placement, but on the effects of moving the individual into an employment status. This model describes a sequence of stages which a disabled person goes through.

A special strength of the Pathways model is the focus on individual economic self-sufficiency, not only a specific type of job placement.
-- PAUL WEHMAN

SUMMARY OF RECOMMENDATIONS

The following is a summary of the recommendations and implications for action developed by the Switzer Scholars as they relate to the topics of Chapter Six. (The recorder was Carl V. Puleo).

1. **Recommendations/Implications that would enhance service delivery.**
   - A. MISSIONS:
     In order that an appropriate high priority be placed on work in the marketplace, all vocational programs should have as a primary emphasis of their mission statement the movement of persons with disabilities into the natural work setting that gives them satisfaction and fulfillment.
   - B. MARKETING
     1. Business and Industry's needs must be identified.
        a. Vocational programs must provide a ready response to industry.
        b. Incentives to hire must be identified, i.e., T.J.T.C.*, on-site support, positive reflection on their rate of return, etc.
     2. Persons with disabilities/families must be marketed toward employment.
     3. Private Industry Councils (PIC) and others must be marketed and sold on the capabilities for work and productivity of persons with disabilities.
   - C. NETWORKING
     Strong productive linkages must be developed and nurtured among several entities by vocational programs.
     1. Education and Rehabilitation
     2. Vocational Education and Special Education
     3. Adult Education, Vocational Education, and Rehabilitation
     4. Vocational, Residential and Recreational

2. **Recommendations/Implications for policy or program development:**
   - A. All policy developed should reflect the intent of the missions statement, i.e., primary emphasis is the movement of persons with disabilities into the neutral work setting.
   - B. The national policy should reflect full employment for all persons.
   - C. The earliest intervention should be made with the systems to assist toward vocational goals.
   - D. Expand the types of environments we train people for as well as the environments in which job placements occur.

3. **Recommendations/Implications for training of staff, the general public, etc.:**
   - A. Pre-service training for rehabilitation professionals. The curriculum should reflect:
     1. A thorough reinforcement that employment is a reasonable outcome for persons with disabilities.
     2. Strong grounding in the concepts of business management, i.e.,
        a. Organizational development
        b. Organizational management
        c. Marketing
   - B. In-Service Training for rehabilitation professionals
     1. Employment is a reasonable outcome for persons with disabilities.
     2. Strategies for relating to the business community.
     3. Focus of this training could be:
        a. University Affiliated Programs (UAPs)
        b. Research and Training Centers (R&Ts)
        c. R.R.C.E.P.s (Continuing Education Programs in Rehabilitation)
        d. P.C.E.H. (President's Committee on Employment of the Handicapped
   - C. Training for Business
     1. Develop training packages targeted to specific groups.
        a. Front line supervision
        b. Personnel staff
        c. Managers
   - D. Employee with disability in-service training.
     1. Develop a strategy whereby there is a workable mechanism for the employer/rehabilitation agency can provide retraining required by technology, job change, etc., without the employee with a disability in danger of losing employment.
   - E. Public Awareness -- Strategy to raise the general level of awareness and sensitivity within the various publics.
     1. Develop awareness information packets for target groups.
        a. Chambers of Commerce
        b. Business professional groups
        c. State business and industry associations

4. Recommendations/Implications for needed research:

A. Develop and utilize program evlauation and measurement of outcome effectiveness for all employment and training programs.

B. Establish a national data base which would reflect the needs of employment and employment related activities.

C. Develop the capacity to support longitudinal research in employment and employment related activities.

D. Research should examine the needs of the marketplace and reflect the needs of the individuals in relationship to the marketplace needs.

5. Recommendations/Implications for legislation - Federal, State, local:

A. It is recommended that the following proposals be considered:

1. Extend the tax credit TJTC (Targeted Job Tax Credit).
2. 1619b - Extend the health care benefit of the Social Security Act.
3. 1619a - Modify to reduce disincentives, adjust the substantial gainful activity (SGA) level. (Social Security Act).
4. Provide better support for employment related expenses, i.e., transportation.
5. Continuation and expansion of demonstration programs for SSI/SSDI** recipients.

**TJTC - Targeted Jobs Tax Credit*

*** SSI- Supplemental Security Income*
SSDI- Social Security Disability Income

Scenes

SOMETHING SPECIAL: Jean Elder, left, Commissioner of Administration on Developmental Disabilities, Department of Health and Human Services, meets with Seminar Chairperson Gary Austin. Elder provided one of the three Special Papers this year.

SCHOLAR STUBBELFIELD: Guy Stubbelfield, National Coordinator for IAM Disabled Worker Program, receives his Switzer Scholar certificate from Leonard Perlman, right, Seminar coordinator with Charles Bradford, left, Program Director, taking part.

SCHOLAR SHEPPARD: Richard Sheppard, right, received his Switzer Scholar certificate from boss Jay Rochlin, Acting Executive Director of the President's Committee on Employment of the Handicapped. Rochlin is a former Scholar.

NRA LEADERS: Two NRA leaders were also Scholars in 1985. At the left is NRCA President Allen Searles with NRA President Amos Sales at the right. Flanked is Gary Austin, NRA Seminar Chairperson

-- *Special Paper* --

Richman

A Transition Initiative Horticulture Hiring the Disabled

By Charles S. Richman
Executive Director
National Council for Therapy and Rehabilitation through Horticulture, Inc.

Since October, 1982 the National Council for Therapy and Rehabilitation through Horticulture has been operating an industry-based job development and placement project. The nationwide effort called **Horticulture Hiring the Disabled (HHD)** is directed at increasing the involvement of horticultural employers in the training and employment of mentally and physically disabled workers. The project is an extension of the overall mission of the National Council which is to promote the expansion, enhancement, and improvement of horticultural therapy and rehabilitation efforts.

The horticulture industry offers a variety of work opportunities from part-time seasonal to full-time positions and from entry-level to highly technical professional jobs. The horticulture field is an expanding part of agri-business both by virtue of the number of employees, number of new or growing firms, and labor-intensiveness. Horticulture is that part of agri-business concerned with intensively cultivated crops (garden crops as contrasted with field crops) used for food, medicinal, or aesthetic/ornamental purposes. It includes not only plant products but also services at the production, wholesale, and retail levels.

Government projections estimate that in the next decade **in excess of 102,000 new entry-level workers** will be required, by horticulture employers. Employers will be recruiting for jobs in nurseries, greenhouses, florists, landscaping, groundskeeping and grounds maintenance, food processing, interior plant care, lawncare, arborist, lawn and garden centers and other related horticulture businesses. This increasing demand for entry-level employees is reflective of other service-type businesses and industries which are not mechanized or automated. Many of these employers seeking large numbers of applicants are currently encountering recruitment difficulties.

Despite accelerating employer demand, the supply of entry-level workers is drying up. We are at the very beginning of a labor shortage period in this country. According to John Naisbitt, author of "Megatrends" and "Re-inventing the Corporation" evidence is mounting that "this country will experience profound labor shortages, beginning in 1985 and continuing through the end of the century and beyond." Because of low birthrates in the past two decades only 1.5 million Americans will be entering the workforce annually, while an average of 3 to 4 million new jobs will be created each year. Many "low tech" or "no tech" jobs will remain unfilled, but also jobs in health, education, business, legal, and financial services will go begging.

A recent article in the Washington Post is headlined "Low-Level Jobs Remain Unfilled -- Firms Near and Far Try Gimmicks to Lure Potential Employees to Work" (Washington Post, November 25, 1985). This article concludes that "the large pool of teenagers and young adults who have historically filled these entry-level positions is shrinking rapidly." Many employers scrambling to fill the gaps left by our country's changing demographics have resorted to various enticements. The article recounts only a few examples of this phenomena:

- Giant Food, Inc. in Rockville and Bethesda, Maryland parks a camper van with a large "Now Hiring -- Apply Within" sign outside busy stores;
- Safeway Stores in Richmond, Virginia are recruiting senior citizens as hard-to-recruit courtesy clerks; in San Francisco Safe is working with the school system to train physically and mentally disabled students to fill the same positions;

- Burger King in Atlanta, New York and other big cities offers educational scholarships to lure teenagers into jobs;
- Roy Rogers uses placemats as employment applications; and,
- The Great American Chocolate Cookie Company offers scholarships to employees at 300 of its franchises.

The New York Times reports similar efforts. In an article entitled "Stamford Stretches Its Labor Pool" (New York Times, January 26, 1986) reports "there are fewer and fewer high school graduates ready to move into first-rung jobs -- as a result, employers have been forced to dig deeper into segments of the labor market formally considered marginal -- high school students, the disabled, the elderly, parolees, and the chronically unemployed." In Stamford, Connecticut each afternoon school-work students report to clerical and secretarial jobs for which regular full-time employees can no longer be found. Pitney Bowes has developed a cash bonus system that encourages employees to recommend friends. Employers are also raising wages, adding day-care facilities, flexible hours and offering more part-time job opportunities. McDonalds provides a free (McShuttle) bus to carry employees from the Bronx to Darien, Connecticut and nationwide is developing a McMaster program to recruit and train senior citizens.

Although this "manpower shortfall" is heavily weighted towards the no-skill, entry-level, minimum wage jobs, evidence is mounting that this trend will eventually affect the entire labor market. Worker scarcity will have a tremendous impact upon the employment prospects of disabled persons once considered marginally productive by prospective employers. Attitudes formed by job placement specialists, rehabilitation counselors and other vocational rehabilitation personnel in a period of job scarcity will need revamping. Perhaps the challenge is the transition of thinking needed to unlearn the bias that jobs are scarce and hard to find for disabled youth -- or for disabled people in general for that matter.

Clearly, programs targeting the transition from school to work for disabled youth will be right on target in supplying badly needed workers for entry-level work. The pent-up demand for the transitioning disabled youth should facilitate the establishment of interagency arrangements, private sector initiatives, projects with industry, supported work, work enclaves, employee leasing and other innovative competitive work options. In the past, many rehabilitation agencies have provided a labor rationing function in which, through a holding action, many disabled clients were retained in day activities or sheltered work programs. The new era will encourage greater outreach into the competitive marketplace.

Through the ongoing job development activities HHD is reaching out as an industry service program to horticultural employers. To date, the project has placed almost 450 mentally and physically disabled workers into competitive employment. Operating through six area offices, supported by contracts for service, the project is providing employee recruitment and screening services for employers. **Area offices are located in major horticultural states including Florida, California, Maryland, Ohio, Pennsylvania and Alabama.** Each area office is advised by a Regional Horticultural Industry Council which guides job development efforts from formulating goals and objectives to identifying market trends. More than one hundred leaders in horticulture business and industry are involved in this partnership process.

Recently, the HHD program has received funding from the U.S. Department of Health and Human Services for HHD-TRANSITIONS, a three year demonstration project to establish a national model for transitioning developmentally disabled young adults from school to work. The project will utilize an industry-based adaptation of the Projects With Industry approach to link horticulture employers with special education, vocational education, and adult service providers. It is expected that at least two exemplary models will be set up which can be replicated elsewhere throughout the country.

A nationwide competition for potential demonstration sponsors was organized late in 1985. This resulted in the competitive awarding of the first demonstration site contract to Goodwill Industries of the Mobile Area, Inc. in Mobile, Alabama. With the addition of a second site in late 1986 it is expected that 210 developmentally disabled youth will be screened and 150 young referred to training or placed into competitive employment. Innovative aspects of the project include:

- close involvement and advisement involving participation of horticulture employers;
- industry-based goals for training and employment;
- utilization of graduated levels of employment preparation including classroom, work experience, work-study, and on-the-job training;
- coordinated case management;
- open-entry/open-exit enrollment aspects; and,

- a focus upon entry-level work skills requirements and qualifications.

Above all the HHD-TRANSITIONS Projects maintain the premise that there will be a sustained and ever increasing demand for entry-level workers by horticulture employers. In conjunction with the HHD-TRANSITIONS Project a national information and industry awareness program is now underway. The goal of this effort is to reach the nursery industry, landscape contractors, bedding plant suppliers, and florists in order to increase their utilization and hiring of disabled workers. During 1985 and 1986 HHD will be appearing at horticultural trade shows, circulating literature to targeted audiences, placing public service ads in trade publications, and sponsoring promotional events. A major advertising campaign will be mounted in 1986 to attract industry-wide attention to the fact that **disabled workers are an untapped manpower resource.** There is no question that the horticulture industry will be hiring thousands of new entry-level employees...and Horticulture Hiring the Disabled is making sure that many of those new hires will be people with disabilities.

Elder

-- *Special Paper* --

Federal Activities to Improve the Transition from School to Adult Services

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U.S. Department of Health and Human Services

Four essential facts about the transition from school to adult life should be emphasized. First, it is not a process that is unique to persons with disabilities. All people encounter this turning point in their lives.

Second, many children, whether disabled or not, require (or could benefit from) services and counseling over and beyond the regular school curriculum in order to prepare them for suitable employment and other adult activities.

Third, the types of transition services needed will differ substantially among different students. It is particularly important to emphasize the different needs among persons who are disabled. In some cases, students with disabilities may require only counseling and some modification of existing vocational educational programs in order to prepare them for employment. In other cases, disabled persons will require specialized training in school and ongoing support as adults. Among the types of ongoing support that may be needed are residential care, modification of jobs, and special supervision while working.

Finally, because of these divergent service needs, the public and private agencies that must be involved in the transition process will vary among different groups of disabled students. In some cases, transition may be effectively handled by the joint efforts of the special education, vocational education, and rehabilitation programs alone. In other cases, mental retardation/developmental disabilities agencies and/or mental health agencies will need to be involved. The involvement of these additional agencies is particularly important when students can benefit from their specialized knowledge, and/or when long-term care and support will be needed after the students leave school.

The current resurgence of interest in transition stems from two developments. First, because of the passage of the Education for all Handicapped Children Act of 1975, thousands of severely disabled young Americans are beginning to exit from the school system who would formerly have been excluded from school. Second, there is rapidly growing awareness that these severely disabled persons are capable of substantial, gainful work, given appropriate services. Unfortunately, many severely disabled persons leaving the school system do not enter into gainful employment, which has been partly attributed to a lack of a transition process (or an inadequate transition process).

In assessing the effectiveness of the transition process for severely disabled students, we must ask three questions. First, is the training and counseling being provided while they are in school appropriate to their needs? Second, is there a procedure to link disabled students with the services and support they will need as adults? Finally, are appropriate adult services available to students making the transition from school to work?

Despite the improvements that are being made in the transition process, there are still many deficiencies. Some of these obstacles to successful transition have been identified in other papers presented at this seminar. There are several, however, that I would like to mention.

First, although almost all disabled children are in school, it is by no means clear that they always receive the type of training which will be most effective in preparing them for employment and other adult activities. This is particularly true for severely disabled students (Bellamy, 1985, Hasazi, 1985, Caparosa, 1985).

Second, after leaving the school system, severely disabled young adults often find that the services that they most need are unavailable. In consequence, many are dead-ended in day activity programs (Bellamy, 1985), languish at home, or are even placed in institutional care (Bruininks, et. al., 1985; Lakin, et. al., 1985).

Finally, the procedures for transition that have been developed to link disabled students to adult services after leaving the school system are frequently inadequate, particularly for students who are developmentally disabled (U.S. Department of Health and Human Services, 1984). Methods to accomplish a smooth transition are, by and large, only just now being developed. Even when they are in place, they sometimes overlook the full range of service needs of severely disabled students. In a recent report in nine exemplary cooperative programs to assist disabled youth in moving from school to competitive employment, the entire focus was on the efforts to coordinate special education, vocational education, and vocational rehabilitation programs (U.S. Department of Education, 1985). Almost no discussion was presented on the importance of involving developmental disabilities/mental retardation offices, mental health offices, and other organizations which will have long-term and sometimes lifelong responsibility for severely disabled persons.

The Federal government is currently sponsoring a number of activities which are designed to improve the transition process. In what follows, I will list several of these activities which will have a substantial direct impact on the effectiveness of transition during the next few years. We should recognize, however, that the list is necessarily incomplete since any improvement in services to disabled children or disabled adults should enhance the effectiveness of the transition process.

Various agencies in the Federal government have invested substantial resources in research and demonstration projects in the areas of transition and employment in recent years. The Department of Education funded 34 demonstration projects to assist handicapped youth in the transition from school to post school activities in 1984. In 1985, an additional 18 demonstration projects were funded which involved cooperative activities between education agencies and adult services agencies in preparing disabled students for the transition from school to work. Many of these projects focus on severely disabled students with the intention of assisting them in obtaining competitive employment. The authority to fund these projects was established in 1983 when Congress amended the Education of the Handicapped Act to establish a Secondary Education and Transition Services for Handicapped Youth Program.

In addition, the Department of Education supported 19 research projects in fiscal years 1984 and 1985 to develop strategies and techniques for transition to independent living, vocational training, and postsecondary education. The Department of Education plans to support two research institutes which will conduct long-term research on the types of skills needed by disabled persons for community living and working, evaluate the effectiveness of various model projects, and explore the implications of the findings from research efforts.

The Administration on Developmental Disabilities in the United States Department of Health and Human Services and the Office of Special Education and Rehabilitative Services in the United States Department of Education are jointly funding demonstrations in ten States to develop supported work opportunities for severely disabled persons. These projects will directly impact the transition process in these States since the target population will encompass persons still in school and the States will develop a process to assist the students make the transition from school to work. Most of the States anticipate working with State Developmental Disabilities/Mental Retardation offices so that long-term continuity of services will be assured. It is anticipated that these programmatic changes can be largely financed by reallocating funds currently being expended on day care activities to supported work activities. It is anticipated that approximately $4.7 million will be expended on these projects during their first year of operation.

During 1984 and 1985, about half of the research funds of the Administration on Developmental Disabilities were expended on research relevant to transition--either to improve transition services for disabled students, or to expand job opportunities for severely disabled persons. Often both purposes were combined in the research projects. The Administration on Developmental Disabilities also helps support 43 University Affiliated Facilities and Satellite Centers to provide training for professionals, services for developmentally disabled persons, and technical assistance to persons and programs serving developmentally disabled persons. Almost half of these University Affiliated Facilities are conducting projects relevant to transition and seven other University Affiliated Facilities are conducting research in the area of supported employment.

During the coming years, as final reports are submitted from these and other research activities, we will greatly expand our understanding of how far we have come, and how much is left to be done, in the area of transition.

In 1984, the Administration on Developmental Disabilities undertook a major initiative to increase work opportunities in competitive employment for developmentally disabled persons. At the start of the initiative, we set a goal of assisting 25,000 individuals with developmental disabilities to obtain competitive jobs in 1984. This goal was raised to 50,000 individuals in 1985 and to 75,000 individuals in 1986. Improving job opportunities is essential to the successful transition of developmentally disabled students to adult life. Among the activities involved in this initiative were:

--The Administration on Developmental Disabilities sent 120,000 letters and response cards to business establishments asking them if they were interested in learning more about why it makes good sense to hire employees with developmental disabilities and inquiring about their employment needs. Over 1200 employers indicated an interest in hiring workers with developmental disabilities and were referred to the State Developmental Disabilities Councils for further assistance. We expect that the proportion of interested employers will increase as they observe how much developmentally disabled workers have contributed to the economic success of their places of employment.

--The Administration on Developmental Disabilities also met with leaders of trade associations and solicited their support. These associations shared information with their membership through newsletters, magazines, and conventions and encouraged their State affiliates to get involved. The National Restaurant Association pledged 10,000 jobs in both 1984 and 1985 and the American Hospital Association is committed to hiring 16,000 employees with developmental disabilities over a two year period. This activity is continuing and additional job pledges are expected from other trade associations.

--State Developmental Disabilities Councils have a major role in the implementation of this initiative. The Developmental Disabilities Councils sponsor employment forums and develop plans for enhancing job opportunities for persons with developmental disabilities in their respective States. The Councils take an active role in assisting developmentally disabled persons to obtain employment. In late 1985, the National Association of Developmental Disabilities Councils (NADDC) voted overwhelmingly to adopt "the development of employment opportunities" as the first priority in their Three Year Plan which began in fiscal year 1986. In addition, the NADDC, with funding from the Administration on Developmental Disabilities, has produced a major technical publication entitled **Guidelines for Evaluating, Reviewing and Enhancing Employment-Related Services for People with Developmental Disabilities** which has been widely disseminated.

--As already noted, a significant part of our discretionary funds were used to promote jobs for developmentally disabled individuals.

The focus of the Administration on Developmental Disabilities on employment will continue. In Public Law 98-527, the Developmental Disabilities Act of 1984, employment-related activities were established as a new priority service area. Employment-related activities encompass incentive programs for employers, transitional services from special education to supported or competitive employment, vocational training and more. By fiscal year 1987, the State plan for developmentally disabled persons must include employment related activities among the priority services to be provided under the plan.

In closing, it is appropriate to emphasize my strong belief that only through cooperative efforts among various State and local agencies can we ensure that individuals with developmental disabilities have the benefit of a continuum of employment-related services which are consistent with their needs and abilities.

□

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-- *Special Paper* --

Martin

Some Thoughts on Transition: A Current Appraisal

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President and Chief Executive Officer
Human Resources Center

Some years ago, I wrote an article called, "Some Thoughts on Mainstreaming" for **Exceptional Children.** (Martin, 1974). As I was preparing this paper on "transitioning," I realized that I was developing parallel thoughts. In the article on "mainstreaming," I detailed the history of unnecessary and in some instances, brutal, segregation that people with disabilities had faced. The correlation between substandard facilities and segregated facilities, particularly in programming for persons with mental retardation and with emotional disturbance, had concerned professionals and parents everywhere. At the same time, separate programs for others, such as those with hearing and physical impairments were not necessarily substandard. In fact, many were recognized to provide excellent education and related services.

In those early 70's, as the movement to pass P.L. 94-142 had begun, it was important to highlight support for the overall direction of greater integration of people with and without disabilities. At the same time, I recognized and cautioned that there was a fad-like attraction to the concept of "mainstreaming." There was a tendency to view decisions on whether or not a child with a disability should be educated with children who were nondisabled in an "all" or "non" fashion. Many believed the only appropriate education for a child with a disability was in a mainstreamed setting. As "The Education For All Handicapped Children Act" was developed, it reflected in good measure the concerns I had described. New incentives for the education of children with disabilities with nondisabled children were provided. However, allowance was made for the possibility of separate educational programs and services depending on the individual child's special education needs. As the Act was drafted, the term "mainstreaming" did not appear, partly, because the concept was seen as one which had become oversimplified and was being used to describe a variety of different possibilities as though they were all identical.

I see parallels today with the concept of "transition." It has become a buzzword like "mainstreaming." It clearly means many different things to many people. In its broadest sense, I think it is an essential and valid concept. There is an inarguable need to improve the employment possibilities for young persons with disabilities who are leaving school. As with "mainstreaming," however, there are fad-like characteristics surrounding the concept of "transitioning."

Let's examine this a bit more. We speak of transition in a manner that suggests that there is a clear and widespread understanding of the nature of the concept -- that there is an "it" called transition denoting a process that can be specified. Coining such a concept is a sound political tactic, because it highlights the issue, gains attention and becomes easier to talk about. However, to be "real" this concept must be shown to have definable properties or characteristics. I would suggest that this task has not, as yet, been accomplished satisfactorily. What we seem to have at this point, as far as I can discern, is that in an ideal world a person eventually leaves the school system and goes on to the world and/or participation as an adult in the community. To make this event occur, some process takes place. Leaving school (or even the preparation to leave school) sets off a chain of events some which are generated by the individual and others which society generates that determine the degree to which this transition leads to successful adulthood. Usually, most of us pass through this stage of life. However, is there really a definable process, which can be studied, generalized and replicated across differing individuals which characterizes this particular stage of life? Can this concept be so defined that makes it amenable for model development and/or to manipulation?

I raise this question -- not as philosophic inquiry or to be argumentative, but because we too often seek to describe complex phenomena with a narrow "label" or classification.

For example, when I was a student in speech therapy, many schools taught treatment of "organic" articulation problems in a different course than "functional" articulation disorders. Later, those classifications were generally discarded as a distinction which was not relevant for training in articulation therapy. Special education classes for children described as mentally retarded or emotionally disturbed, often were based on an assumption of homogeneity of children with those "labels," but in fact the children behave quite heterogeneously. "Learning disabilities" is a term that seems to cover many different phenomena, but implies one entity, and I believe considerable confusion has resulted from trying to identify complex phenomena with a single label or term.

In this regard, "transitioning" should not be conceived of as a universal process undertaken to reach a common endstate -- i.e., successful employment. Rather, it is more likely that "transitioning" encompasses a multiplicity of means undertaken to reach a wide variety of ends, and contingent on individual differences of the people involved.

We will need to be very careful in assuming that individuals with different disabilities and who demonstrate different degrees of functioning ability may be able to achieve identical goals. It seems to me that as I have attended conferences and read publications that these variations are frequently brushed over. As with mainstreaming, the goals are so attractive that only a few people want to look too closely at the possibility of problems occurring that do not fit the desired model.

I have heard presentations that emphasized the value of real work in integrated environments that quickly glossed over the fact that it had not been possible to arrange a situation where this work was paid for at minimum wage levels, yet it was treated as though competitive work placements had been accomplished. Often, the claims have not matched the reality. For persons with severe disabilities, paid work in the competitive world may not always be feasible. Perhaps it is a realistic goal for some, or even many, but we need to determine by individual analysis which goals are realistic for which people and in what specific environments. In any event, my point is that enthusiasm for a concept often drives professionals to emphasize only the positive outcomes and perhaps overlook the less desirable possibilities that may be just as real.

Festinger, a social psychologist, has written about a concept he called Cognitive Dissonance (Festinger, 1957). What he suggested was that people will sometimes misperceive situations in which the actual phenomena are too different from a strongly held belief. An individual in this context cannot deal with the gap or dissonance, and so changes the facts, unconsciously, to better fit.

I do not want to go on in this cautionary way too long, because my point is not to throw the baby out with the bath water, but to emphasize that popular concepts in education and rehabilitation often race ahead of science and sometimes are so desirable that professionals do not want to see problems that do not fit their models.

Some Other Dimensions

What are some other dimensions of what has been called "transition" that seem significant to me?

First, the term anticipates an active process. This is important because too frequently in the past, young people drifted between school and vocational rehabilitation agencies, other agencies, or, of course, the work situation itself. Current transition projects are trying to influence the entire process and change the nature of some existing situations at school, in social service agencies, and at work sites.

For example, job coaches expand rehabilitation and education from the classroom to the work site, and also may vary the traditional roles that teachers or rehabilitation counselors play.

Is the job coach a successful, proven model of "transitioning?" During this conference, you will hear about one of the leading, most established programs (Vera Institute's "Job Path") and its accomplishments. Should we all rush out to begin such programs? I think it is a little too early to know. The developers of projects in this area must be given more time to live with this model, learn from it and perhaps change and modify it.

Although I am not expert in job-coach programs, I would imagine these will be difficult programs to sustain. Perhaps not impossible, but difficult, because the role of the job coach is somewhat new and does not follow old established models. We do not know what the pressures on job coaches may be over long periods of time. Will they tire of travel? Will they wish they could spend more time in one setting like an office or classroom as do other professionals? Will they get recruited away by the industries with whom they are working as their friendships and networks grow? These are just some layman's guesses of possible growing pains in a very attractive approach to facilitating employment. What is important is that as we grow and develop we do not expect trouble-free growth and development nor assume that there will be one best approach. What we must do, however, is to be committed to evaluation and research on the concepts in which we believe most strongly. As Festinger points out, accepting dissonant data is not easy for individuals, but the method of science helps overcome these more subjective responses.

The job coach is a good example of an active process -- an attempt to go out and make something happen in the work situation that might not otherwise occur. What about the classroom? Will the school really change what it does in the sophomore, junior, senior, or earlier years? If I guess right, change will not be easy to achieve. School programs have strong curricula direction from state and local officials. In New York, for example, the Regents (the equivalent of the State Board of Education) have just gone through a process designed to raise standards and improve the quality of education. New requirements in science, language, etc., have been added. The effect on the high school at our Center has been to take away time that has been available for vocational evaluation and job readiness activities. The impact of "higher standards" on "transition" may be quite negative.

Restructuring within school activities will require great effort and persistance. The national experience with the grudgingly slow progress modifying vocational education to serve young people with disabilities is yet another example of the difficulties to be faced.

Changes in the rehabilitation agency's functioning will also not necessarily be easy. For example, when I served as Assistant Secretary for Special Education and Rehabilitative Services in Washington, I discovered how difficult it was to get the agencies I headed to accept individuals with learning disabilities as valid candidates for vocational rehabilitation services under the federal-state programs. How will "supported work" programs fit into the services offered under the auspices of federal and state rehabilitation agencies?

As professionals rightfully strive to avoid having persons with severe disabilities sit idly or do "busy work," attempts are being made to create work situations where costs are partially paid by third-party agencies and not the employer, in recognition of the limited abilities of the workers. For some persons, such programs may need to be permanent. In a sense, some may see this as an improved model of the sheltered workshop. Some state rehabilitation agency personnel fear financial support for such a program will come at the expense of activities designed for persons with disabilities who may be able to be placed in competitive employment. Joseph Dusenbury, Head of the Vocational Rehabilitation Agency in South Carolina and recent Chairman of the National Council on the Handicapped has recently presented this point of view. He questions whether vocational rehabilitation agencies are the appropriate funding agencies for supported work programs.

Employers, too, will be asked to change some of their accustomed ways. This is not an entirely new idea. Some employers have made accommodations for many years. We find, however, that achieving other kinds of changes in job function or design are more difficult. For example, a bright deaf worker may be locked in a dead-end job because the next step up the ladder is a job where using a phone has been necessary. For a rehabilitation program to identify that situation; to secure the willingness of the company to change its pattern, and perhaps, most significantly, to ensure that such a change is a benefit to the company as well as the employee, is a more complicated task than getting the person hired in an entry-level job. We have always told employers that working with rehabilitation programs will bring benefits. Are we truly prepared to back up this statement in the case of clients who may not be competitively productive?

Regardless of how important "transition" is, it is only the beginning of someone's career. What will happen to these workers in the future? At Human Resources Center, we are beginning a new model project, which may be a first in the nation, designed to see if we can successfully assist individuals to move up the job ladder when they are in dead-end situations. Happily, we are finding that personnel specialists of some major employers, members of our National Industry Labor Council are also interesteed in this issue. We will offer vocational evaluation, counseling, special skill training and placement services to workers with disabilities to assist in their career advancement -- a new kind of "transitioning."

In conclusion, to effectively help more young people achieve employment, we have our work cut out for us and we must avoid sloganeering and overly simple solutions. I am pleased to have had the opportunity to provide "Some Thoughts on Transitioning." If I seem to have come like Mark Anthony, there is another level of my message which affirms the work we do.

Helping persons with disabilities find meaningful and gainful work is extraordinarily significant and I feel extraordinarily difficult in many instances, but also as extraordinarily satisfying when accomplished. At the same time, it is my wish to express a need for caution.

As professionals, we should guard against becoming overly committed to popular concepts and approaches. We should avoid rusing to embrace attractive solutions without paying the price of study and evaluation over reasonably lengthy periods of time. We should be willing to accept that progress will not be without pain, that old is not necessarily bad. Instead, tradition is sometimes the correct product of practical experience and we should dedicate ourselves to staying committed for a long struggle, constantly searching for improved policies and practices.

As I have said in many forums, there have been centuries of discrimination against people with disabilities, across many cultures. These problems of attitude are not all gone, nor will they go away quickly. Further, there are very real problems which we must not deny in our wish for rapid success and worthy outcomes.

Most significantly, however, we should take heart that we are about a marvelous work. We are affirming the dignity and worth of each human life. Is that an important thing to do? I think so. I think we would live in a peaceful worlnot all gone, nor will they go away quickly. Further, there are very real problems which we must not deny in our wish for rapid success and worthy outcomes.

Most significantly, however, we should take heart that we are about a marvelous work. We are affirming the dignity and worth of each human life. Is

that an important thing to do? I think so. I think we would live in a peaceful world if each person would follow such a path. We cannot solve the world's problems signle-handedly, but we can make our personal mark.

Thank you and God speed to each of you in your efforts to bring about meaningful work opportunities for persons with disabilities.

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Master List of Switzer Scholars

FIRST SWITZER SEMINAR

Cleveland, Ohio -- May 20-23, 1975

"Pathology, Impairment, Functional Limitation And Disability -- Implications for Practice, Research, Program and Policy Development and Service Delivery"

Fred Addison
Lithonia, Ga.
Olive Banister
Cleveland, Ohio
Monroe Berkowitz
New Brunswich, N.J.
Richard D. Burk
Dayton, Ohio
Barry P. Craig
Charlottesville, Va.
Raymond A. Ehrle
Washington, D.C.
Rod Ferrell
Washington, D.C.
August Gehrke
St. Paul, Minn.
Carl V. Granger
Boston, Mass.
Lawrence Haber
Baltimore, Md.
Joseph Hunt
Arlington, Va.
William A. McDowell
Huntington, W.V.
Joseph Moriarity
South Charleston, W.V.
Saad Nagi
Columbus, Ohio
C. Esco Obermann
Afton, Minn.
Leonard G. Perlman
Rockville, Md.
Dean Taylor
Richmond, Va.
E.B. Whitten
McLean, Va.

SECOND SWITZER SEMINAR

New York, New York -- January 17-19, 1977

"Rehabilitation of the Older Blind Person: A Shared Responsibility"

Willis W. Atwell
Washington, D.C.
Duane Balentine
Little Rock, Ark.
Mary K. Bauman
Philadelphia, Pa.
Robert Carolan
Providence, R.I.
William T. Coppage
Richmond, Va.
Dorothy Demby
New York, N.Y.
S. Saul Freedman
New York, N.Y.
George Gillispie
Washington, D.C.
Helen Gromann
Newark, N.J.
Leonard G. Perlman, Coordinator
Rockville, Md.
Douglas E. Inkster
New York, N.Y.
Ruth Kaarlela
Kalamazoo, Mich.
George A. Magers
Washington, D.C.
Betty Maloney
Brooklyn, N.Y.
Melvin Saterbak
Minneapolis, Minn.
Irving P. Schloss
Washington, D.C.
Daniel Sinick
Washington, D.C.
Bonny Russell
Atherton, Calif.
Joseph Hunt
Chairperson

THIRD SWITZER SEMINAR

Denver, Colorado - December, 1978

"The Role of Vocational Rehabilitation in the 1980's Serving Those With Invisible Handicaps Such As Cancer, Cardiac Illness, Epilepsy"

Olive Banister
Cleveland, Ohio
Abraham Brickner
Detroit, Mich.
Sterling B. Brinkley
Washington, D.C.
Lawrence D. Burke
Bethesda, Md.
G. Fred Cromes, Jr.
Dallas, Tex.
William Gellman
Chicago, Ill.
John Goldschmidt
Chicago, Ill.
Hank Graden
Raleigh, NC
Morris C. Hansen
Salt Lake City, Utah
James F. Garrett, Chairperson
Washington, D.C.
Lawrence C. Hartlage
Augusta, Ga.
Betty Hedgeman
New York, N.Y.
Melvin J. Krant
Worchester, Mass.
Robert M. Levenson
Seattle, Wash.
matthew Maxon
Dallas, Tex.
David I. Mostofsky
Boston, Mass.
Joyce Pigg
Redwood City, Calif.
Judy Spolum
Denver, Colo.
Jerry L. Starkweather
Des Moines, Ia.
Leonard G. Perlman, Coordinator
Rockville, Md.

FOURTH SWITZER SEMINAR

New York, New York -- February, 1980

"The Rehabilitation of the Mentally Ill in the 1980's"

Sheila H. Akabas
New York, N.Y.
William A. Anthony
Boston, Mass.
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Durham, N.C.
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FIFTH SWITZER SEMINAR

New York, New York -- March, 1980

"International Aspects of Rehabilitation Of Disabled Persons: Policy Guidance for the 1980s"

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Washington, D.C.
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Montivideo, Uraguay
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G. Allan Roeher
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SIXTH SWITZER SEMINAR

Washington, D.C. - November 16-18, 1981

"Women and Rehabilitation of Disabled Persons"

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Bobbie Atkins
Milwaukee, Wisc.
Joan Thompson Barker
Versailles, Ky.
Martha Carrick
Atlanta, Ga.
Susan Flowers Dixon
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Billie Elder
Little Rock, Ark.
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Harold Snider
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East Lansing, Mich.
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Carolyn Vash
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SEVENTH SWITZER SEMINAR

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**"Rehabilitation in the Public Mind:
Strategies of Marketing"**

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Shirley Bonnem
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Cedarhurst, N.Y.
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Eunice Fiorito
Washington, D.C.
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Jinny Spann
Dunbar, W.V.
Peter Vail
Norman, Okla.
Jack Victor
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EIGHTH SWITZER SEMINAR

Washington, District of Columbia - November 16-18, 1983

**"Technology and Rehabilitation of Disabled Persons
In the Information Age"**

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Despite the demands on the national and federal scene, her presence was almost ubiquitous in behalf of program development and extended services to needy people. On a regional, state or local level, be it public or voluntary services, if it were in the interest of rehabilitating those in need, somehow, she would "arrange to be there."

The WHO'S WHOs has chronicled her many national and international awards. Also recorded are her presidencies of many organizations including NRA, whose members and their efforts she held in high esteem. But she did not reach the heights of her ability when she was made the first Administrator of the Social Rehabilitation Services, not when she retired from the position, nor when she became internationally involved in the World Rehabilitation Fund. Instead, she found her greatness when she touched each of us bringing our full humanitarian efforts and qualities to the fore in behalf of disabled and disadvantaged people. While readily recognized as a truly great administrator in the classical sense of the word, her true capacity and ability can only be appreciated when we realize that these accomplishments sprang from an inner expression of sensitivity, emotional refinement and dedication to serve all less fortunate people. Her egalitarian qualities were not contrived but spontaneous, stemming from love and respect for all living things.

All of us in NRA and in rehabilitation and all handicapped people have had better, more meaningful, and more productive lives because her presence and her being were sufficiently large to embrace and accept us as we are and help us better understand where we should be.

What more can be said than that we had the joy and privilege of knowing her?

This memorial tribute is quoted from E.B. Whitten,
Journal of Rehabilitation, November/December, 1971

Mary E. Switzer Memorial

To perpetuate the memory of a great woman and a great leader in the field of Rehabilitation by establishing a memorial that will expand and enrich services to individuals with disabilities.